



Department  
for Education

Research Report DFE-RR232b

# **Evaluation of the extended individual budget pilot programme for families with disabled children: the family journey one year on**

**Rhian Johnson & Graham Thom, SQW**

The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

# Contents

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Acknowledgements.....	i
The team .....	ii
Executive summary.....	iii
1: Introduction .....	1
2: The original cohort of families taking part in the pilot.....	6
3: The IB review process.....	18
4: Outcomes achieved by the original cohort of participating families.....	26
5: Impacts achieved by the original cohort of participating families.....	40
6: Conclusions and implications.....	53

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<b>Contact:</b>	Meera Prabhakar	Tel:	020 7307 7151	email:	<a href="mailto:mprabhakar@sqw.co.uk">mprabhakar@sqw.co.uk</a>
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<b>Approved by:</b>	Graham Thom	Date:	31/07/12
	Director		

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## **Acknowledgements**

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## The team

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SQW was commissioned by the Department for Education (DfE) to lead a consortium to undertake the evaluation and support of the extended year of the Individual Budget (IB) Pilot Programme for Families with Disabled Children. The consortium comprised of SQW, Ipsos MORI and iMPower, and drew upon expert advice from individual health and education specialists.

**Graham Thom**, a Director at SQW, acted as the overall Project Director.

**Meera Prabhakar**, a Senior Consultant at SQW, acted as the overall Project Manager.

Rhian Johnson, Laura Henderson, Jennifer Hurstfield, Lisa McCrindle, Robert Turner and Tarran Macmillan formed the other members of the SQW research team.

**Claire Lambert** and **David Jeans** acted as the leads for Ipsos MORI.

Expert health and education expertise was provided by **Rob Whiteford**, **Professor Anne West** and **Phillip Noden**.

**David Colbear** acted as the lead for iMPower.

## Executive summary

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1. This report is one of two volumes containing the findings from the extended year of the Individual Budget (IB) Pilot Programme for families with disabled children. The two volumes cover:
  - *The Extended Packages*, which provides an assessment of how the pilot sites sought to broaden their IB offer to include both education and health funding, and the challenges associated with this
  - *The Family Journey One Year On*, which provides an update on the position and views of the original cohort of families that participated in the IB pilot 12-18 months after they began to receive their IB payments - **these issues are contained in this volume.**
2. The IB pilots were originally commissioned to run from April 2009 to March 2011 by the former Department for Children, Schools and Families (DCSF), to establish if an IB:
  - Enabled disabled children and their families to have more choice and control over the delivery of their support package
  - Improved outcomes for some, or all, disabled children and their families.
3. The programme operated in six pilot local authority areas.
4. The original cohort consisted of 189 families engaged in the pilot by March 2010. Of these, 173 (92%) completed the 2010 baseline survey, 126 (67%) also completed the 2011 Wave 2 survey and 78 (41%) also completed the 2012 Wave 3 survey. The characteristics of families still engaged at Wave 3 were broadly in line (proportionately) with the original cohort.
5. Certain groups (existing social care users, families from lower social grades, young people aged 16+ at baseline and those with lower level needs) were more likely to leave the pilot; either through choice or transition into adult services. Families most commonly left the pilot before finishing support planning. A small number of families did drop out once in receipt of their IB – but this tended to be because they no longer required support, rather than that they were dissatisfied with their IB.

## The IB review process

6. The review process has tended to check that the agreed support plan was working as intended to achieve the agreed outcomes, rather than to revisit the assessment or resource allocation. Just over two fifths of families did not experience a change in package through their review. However, a number of budgets changed at review, with an average increase of £1,473.
7. Most changes were relatively small, yet in some cases package costs were revised dramatically at review. The largest changes in budget have been increases rather than decreases; five families had increases in their budget of more than £11,000. Such **large changes tended to reflect a significant change in the needs of the young person, rather than indicating an issue with the original allocation process.**
8. The majority of families felt that the views of themselves and their family were taken into account during the last review process. Social workers also perceived the IB review process to be more inclusive, supportive and person centred than before and 'much more positive' than other types of review.
9. The most common changes in service provision were increases and decreases to provision of personal assistants and short breaks. On balance, **the use of personal assistants appears to have increased and the use of short breaks decreased.** However, the changes were often small and reflected changing needs of the family, or in some cases families were reported to be becoming more creative in the use of their IB as they became more experienced.

## Outcomes achieved by families

10. **The survey findings indicate that 12 months after the last survey the net improvements in outcomes have generally been sustained at Wave 3,** but in most cases have not become more widespread. Despite already having relatively high levels of involvement in decision making prior to receiving an IB, the IB has led to a net improvement in around one quarter of families.
11. The majority of families experienced an increase in control over the help they receive in relation to their child/young person's disability (net improvement of +54% by Wave 3), while satisfaction with the help received in relation to their child/young person's disability also improved (a net improvement of +45% by Wave 3). A Wilcoxon Signed

Ranks Test on the responses from all families showed statistically significant improvements between the baseline and Wave 3 responses across both indicators.

12. Access to the social care services required has increased considerably since the baseline (a net improvement of +47% by Wave 3). While still a strongly positive and statistically significant improvement from the baseline, the net improvement has fallen back from the +63% improvement reported by Wave 2.
13. The improved outcomes were fairly widely distributed, with almost two-thirds of families reporting improvements in four or more of the outcome indicators.

### Impacts achieved by families

14. One year on from Wave 2 the net improvements in impacts have, for the most part been sustained, although they have not been experienced more widely as families acclimatised to their new packages of support. This repeats the findings around outcomes.
15. Changes over the course of the pilot (baseline to Wave 3) are set out below against elements of the Every Child Matters framework, which was selected in 2009 as the basis against which the original set of pilot impacts were developed:
  - Be healthy – The health of a quarter (24%) of children/young people was perceived to have improved since the baseline, while the health of 21% had deteriorated. The overarching change in health over the course of the pilot was not statistically significant, meaning we were unable to rule out the possibility that the change occurred by chance rather than reflecting a pattern of improvement, and so we cannot be confident that such changes would occur across a wider population. Also, given the limited direct engagement of health, factors outside the pilot are also likely to have been key to any changes.
  - Stay safe – Since enrolling on the pilot, there have been net decreases in levels of parental concern over the children/young people's safety when undertaking activities inside (+19%) and outside (+24%) the home. Both changes are statistically significant. The pilot has provided children/young people with increased opportunities to socialise through the use of personal assistants.



- Enjoy and achieve – There has been some net improvement in perceptions of the children/young people's attainment (+15%) and enjoyment (+9%) of school since the baseline, although these changes were not statistically significant.
- Making a positive contribution – Since the baseline, there have been statistically significant net improvements in both parents (+27%) and their children's (+35%) social lives. Increased use of personal assistants is likely to have been a factor in these improvements.
- Achieve economic wellbeing – There had been net improvements in quality of life for around one quarter of parents and young people, which was statistically significant. Six parents also entered employment from the baseline, in some cases as a direct result of the pilot.

## Conclusions and implications

16. Most families in the pilot that engaged in the IB process have remained in receipt of their IB package. High retention and positive feedback about the review process would suggest that **many families in the pilot have accepted and welcomed the IB approach.**
17. The reasons behind families' satisfaction with the process are indicated by **most frequently reported outcomes**, around:
  - **Access to social care services**
  - **Control over services received**
  - **Satisfaction with the support received.**
18. It is likely that these bullet points reinforce each other, i.e. that improved access and control will lead to increased satisfaction. That said, it is interesting that satisfaction has actually gone up least of the three indicators, perhaps suggesting how challenging some circumstances or indeed family demands are (or perhaps that levels of expectation have risen over the life of the pilot).
19. Although most families gained something, it also appears that **those most likely to report improved outcomes are those who were initially less satisfied.** So, while some families who were satisfied to begin with became more satisfied; it was more

common for families who were not previously satisfied to become satisfied across a number of the indicators.

20. This is potentially important in terms of a wider roll out as the extent of any gains in outcomes achieved will depend on the initial level of satisfaction. It would suggest that in targeting or phasing any rollout it may be best to begin with those families that are expressing dissatisfaction as this is where most benefit will be gained. Indeed, this type of 'problem solving' approach is one that we have observed in the IB pilots whereby the IB approach has been used to provide a more tailored and flexible approach to difficult cases.
21. The **most commonly reported impacts are the improved social life of both the child/young person and the family, and improved family togetherness**. These impacts are similar to those reported in the previous wave of the survey, again indicating that **where benefits arise they tend to be maintained**.
22. However, the **reported impacts are considerably less widespread than the achieved outcomes**. The net change in impacts ranges from 3-35%, compared to 24-54% for outcomes (and the changes are statistically significant for just over half of the impact indicators compared to almost all of the outcome indicators). We had anticipated that the level of impacts would grow over time as a result of families improved access to services that better suited their needs. This chain of impact appears not to have developed as hoped, and given the time that has passed it seems unlikely that they will.
23. While the level of impacts has not increased as hoped, it should be remembered that **most families did report improvements on some indicators and that most families are happier with the support that they receive**. And, as with outcomes, there are relatively limited negative effects in terms of impacts. So, if going forward the key policy objective is to increase choice and control, then that has broadly been achieved. If however, the expectation is that choice and control will in turn improve impacts, then the results are less conclusive.
24. This leaves a dilemma around both the IB approach as piloted and the wider SEND Pathfinders. One option would be to focus on families that are unhappy with their current offer. Perhaps where families are broadly happy with their current support then in moving to an IB approach the level of investment around these families should be fairly limited. For example, the amount of time and effort invested in support planning could be limited on the grounds that relatively little needs to change.

25. The second, more positive, option is to take the initially more expensive, holistic approach across education, health and social care in the expectation that this will lead to greater benefits. The evidence generated by the on-going SEND Pathfinders will be crucial in demonstrating if these greater benefits can be evidenced.

# 1: Introduction

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## Purpose of this report

- 1.1 This report is one of two volumes containing the findings from the extended year of the Individual Budget (IB) Pilot Programme for families with disabled children. The two volumes cover:
- *The Extended Packages*, which provides an assessment of how the pilot sites sought to broaden their IB offer to include both education and health funding, and the challenges associated with this
  - *The Family Journey One Year On*, which provides an update on the position and views of the original cohort of families that participated in the IB pilot 12-18 months after they began to receive their IB payments - **these issues are contained in this volume.**

## The extended Individual Budgets programme

- 1.2 The IB pilots were originally commissioned to run from April 2009 to March 2011 by the former Department for Children, Schools and Families (DCSF), to establish if an IB:
- Enabled disabled children and their families to have more choice and control over the delivery of their support package
  - Improved outcomes for some, or all, disabled children and their families.
- 1.3 The Individual Budget (IB) approach was built on the premise that it offered greater choice and control to families with disabled children through the drawing together of a series of funding streams and use of an outcomes-based approach. This would enable the development and delivery of a holistic and family-led support plan, with the option to manage the associated funding in a variety of ways.
- 1.4 The programme operated in six pilot local authority areas (Coventry, Derbyshire, Essex, Gateshead, Gloucestershire and Newcastle), each of which generated a wealth of information and learning about the introduction of IBs for families with disabled children<sup>1</sup>. However, much of the evidence was based on the inclusion of

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<sup>1</sup> The suite of reports from the original two year evaluation of the IB Pilot Programme can be found at <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR145>

only or very largely social care funding in the IB packages, as in most cases it proved difficult for the social care led pilots to gain the active involvement of health and education colleagues. As such the health and education monies were often limited, for example to very specific items or to nominal amounts of money.

1.5 Broadening the IB packages would require the pilots to address a series of barriers that were identified in the original evaluation report:

- The commitment of other services – this was often weak and it remained to be seen how health practitioners, schools and others would commit to the process
- Technical issues around unpacking the budget of an individual in the context of block funding and contracts
- Concerns as to how far families were best placed to judge the most appropriate course of action around education needs (where the emphasis had been on teachers developing personal learning plans for pupils) and in health, especially around clinical judgements.

1.6 Similarly, although the pilots demonstrated a clear linkage between the use of the IB approach and an increased sense of choice, control and satisfaction on the part of families, limited time had passed for the change in process to lead to changes in wellbeing. It was therefore unclear how far the initial short-term outcomes would lead to improved sustained impacts on wellbeing across the group of families.

1.7 In May 2011, and following the change in Government in 2010 when delivery of the Programme passed to the Department for Education (DfE), the six IB pilots were extended to run for an additional year (i.e. 2011-12). With the extension came an expectation that the pilots would:

- Test how they could broaden their offer to include Education and Health funds/services into their IB packages
- Continue to support the cohort of families that had participated in the original pilot, to enable the tracking of distance travelled by these families during the extended year, as a means of understanding whether the approach led to improved wellbeing.

1.8 The change in Government also led to a Special Educational Needs and Disability (SEND) Green Paper, which provided further context for taking forward the extended IB Pilot Programme. The SEND Green Paper highlighted the Government's wish to:

- Give parents the option of a personal budget (*which in this context is the same as an IB*) by 2014, linked to a new 'single plan' which was to draw together education, health and social care services, to give them greater control over their child's support, with key workers helping them to navigate different services
- Recruit a set of Pathfinders to test the best ways to provide a personal budget to children with SEN and/or disabilities, linked to the new plan, building on findings from the IB pilots.

1.9 The development of the extended IB Pilot Programme was therefore likely to be strongly influenced by the concurrent development of the SEND Pathfinder Programme. This created a possibility/expectation that the two programmes would run together to enable the original IB work and experiences to roll forward into the development of an assessment and single plan pathway.

### Our extended evaluation and support approach

1.10 Given the intentions set out in the SEND Green Paper, the focus for the third year of the pilots was to gain effective buy-in from education and health agencies, as a means of broadening the scope of the IB packages. Our approach to the evaluation of the extended programme was therefore developed to ensure consistency with the work undertaken during the preceding evaluation along with a broader perspective to reflect changing policy aspirations.

1.11 The approach incorporated a mix of on-the-ground research/support and desk based research. The work programme was divided into three strands, each of which was delivered simultaneously by different parts of the research and support consortium:

- **Scoping strand** – in-depth strategic work with social care, education and health colleagues was undertaken in each of the pilot sites over the course of the first three months of the extension (i.e. late May-August 2011) as a means of identifying the challenges faced in drawing together resources from the three agencies and how these issues might be worked through

- **Evaluation strand** – the evaluation research undertaken during the first two years of the pilot programme was extended, to enable the tracking of both the IB process and distance travelled by the families over an additional year
- **Support strand** – bespoke on-site support was offered and then provided on an ad hoc basis, as requested by sites.

## Methodology

1.12 Table 1 provides a description of the research and support that was undertaken.

Table 1: Research and support undertaken during the extended year of the IB Pilot Programme	
Research Method	Description
<b>Scoping</b>	
<b>On site development support and wider consultation</b>	<ul style="list-style-type: none"> <li>• Liaison with the six IB pilot sites, other areas which are taking forward IB related work and subject experts to more fully understand what could be possible and achievable in terms of bringing wider funding streams into an IB</li> </ul>
<b>Two workshops</b>	<ul style="list-style-type: none"> <li>• Pilot site workshops held in May and August 2011</li> </ul>
<b>Development of health and education 'scoping' papers</b>	<ul style="list-style-type: none"> <li>• Development of health and education scoping papers which set out some of the options and possible paths for local areas to explore – <i>see separate reports</i></li> </ul>
<b>Review and finalisation of delivery plans</b>	<ul style="list-style-type: none"> <li>• Support to complete year three delivery plans</li> </ul>
<b>Evaluation</b>	
<b>Area case study fieldwork</b>	<ul style="list-style-type: none"> <li>• 3 rounds of case study fieldwork were undertaken with each of the sites, involving detailed consultations with key partners in each of the six areas</li> </ul>
<b>Monitoring</b>	<ul style="list-style-type: none"> <li>• Four monitoring submission for 2011/12 were received and analysed</li> </ul>
<b>Workshop</b>	<ul style="list-style-type: none"> <li>• Pilot site workshop held in Jan 2012 to share lessons learned</li> </ul>
<b>Wave 3 family survey</b>	<ul style="list-style-type: none"> <li>• Wave 3 family survey undertaken over the course of Jan-Feb 2012 with families who took up the original IB offer and were surveyed in 2010 and 2011.</li> </ul>
<b>Support and challenge</b>	
<b>Development of bespoke support</b>	<ul style="list-style-type: none"> <li>• Tailored packages of support delivered to two sites to support development of: <ul style="list-style-type: none"> <li>➢ Health-related extension activities</li> <li>➢ Shared objectives and processes between strategic partners</li> <li>➢ Development of education transport budgets</li> </ul> </li> <li>• On-going support and feedback was provided to sites when requested</li> </ul>

- 1.13 A total of 78 parent-carers<sup>2</sup> were interviewed in Wave 3. In addition to parent interviews, 18 young people were interviewed in these households. The number of interviews was restricted by the age range and the severity of disability of many of the client group. Due to the small numbers we have reported the findings of the young people only at key points in the report, and treated these results as indicative. A fuller description of the methodology can be found in the separate Technical Report.

## Report structure

- 1.14 This report seeks to present a detailed assessment of the *process related* progress made by the pilot sites over the extended year, including progress made in relation to the: *inclusion of education and health funding into IB packages*; and the *development of wider infrastructure associated with an extension of the IB approach*.
- 1.15 The remainder of the report is structured as follows:
- Chapter 2: describes the cohort of families who responded to the survey
  - Chapter 3: details the IB review process
  - Chapter 4: reports on the outcomes achieved by families
  - Chapter 5: reports on the impacts achieved by families
  - Chapter 6: sets out our key findings and implications arising from them.

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<sup>2</sup> Throughout the rest of the report we have used the terms parents to refer to parent-carers.



## 2: The original cohort of families taking part in the pilot

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### Introduction

- 2.1 This chapter introduces the families that signed up to the pilot. It describes the characteristics of the 78 families that were still engaged in the pilot and responded to the Wave 3 survey, two years after the initial baseline survey. It then examines the families that have left the pilot.

### Families taking part in the pilot

- 2.2 Each of the IB pilot sites was tasked to engage 30-50 families with disabled children to take part in the pilot. Across the six sites, 189 families were engaged in the pilot by March 2010. The experiences of these families were tracked through surveys of the families, disabled children and young people, and site monitoring data. The surveys were conducted on a before and after basis. The initial questionnaire gathered baseline data on the position of the family prior to its receipt of an IB. The same families were then revisited, using the same questions one year and two years later to assess the distance travelled by families after they had engaged in the IB process.
- 2.3 The baseline (Wave 1) survey was completed by 173 families. Almost three quarters of these families (126) went on to complete the Wave 2 survey in early 2011. As part of the extension of the pilot, a further wave of the survey was conducted with families who had participated in the baseline and Wave 2 surveys, to understand whether there had been changes in perceptions two years on from the baseline survey. A total of 78 families completed the Wave 3 survey, 41% of the original cohort and 61% of families still reported to be on the pilot.
- 2.4 The main reason for follow up interviews not being conducted was that 62 of the families had left the pilot since participating in the baseline survey (either because they had chosen to leave the pilot or the young person had reached 18 and transitioned into adult services).<sup>3</sup> The characteristics of all families who left the pilot are explored later in this chapter.

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<sup>3</sup> The remaining families did not complete the Wave 3 survey, either because they had not completed the Wave 2 survey, because they could not be contacted, or were unable to commit to an appointment during the evaluation timescales or they refused the consultation due to personal circumstances (for instance because their child was ill).

## Nature of the surveyed families

- 2.5 The *Interim Report*<sup>4</sup> described the characteristics of participating families who signed up to the pilot by March 2010, and *The Family Journey* report<sup>5</sup> provided an update on families still engaged a year later. They showed a good level of diversity across participating families in relation to: socio economic status; the nature of the child/young person's disability; and previous use of personalised approaches.

### **Characteristics of families**

- 2.6 At the time of the Wave 3 survey, just over a third of children/young people on the pilot (35%) were from single parent families, which was largely unchanged from the baseline. Nationally 22%<sup>6</sup> of households with dependent children are lone parent families.
- 2.7 On average pilot families had 2.0 children under the age of 18 at Wave 3, compared to a national average of 1.8 children per family.<sup>7</sup>

### **Family economic status**

- 2.8 The overall employment status of families did not vary substantially over the course of the pilot. In 60% of cases the responding parent was not in full-time or part-time employment at the time of the Wave 3 survey. This included 50% of families where the parent was at home/not seeking work, and a further 5% where the parent described themselves as being long-term sick or disabled (Table 2).
- 2.9 In just under one third of households (31%) no-one was working at the time of the Wave 3 survey. However, where the enrolled child/young person lived in a dual parent household, the second parent tended to work full-time.

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<sup>4</sup> Prabhakar, M., Thom, G., Johnson, R., 2010, *Individual Budgets for Families with Disabled Children: Interim Report 2010*

<sup>5</sup> Johnson, R., Thom, G., Prabhakar, M., 2011, *Individual budgets for families with disabled children: Final evaluation report: The family journey*

<sup>6</sup> This figure is calculated using 2001 Census data. It calculates the proportion of all households with at least one dependent child that were lone parent families.

<sup>7</sup> The national average figure was calculated using 2001 Census data. It calculates the average number of dependent children (aged 0-18) per household with dependent children. This differs slightly from the IB definition, where children are aged under 18.

Table 2: Employment status of parents in the household

	Employment status of responding parent		Employment status of second parent	
	N	%	N	%
Working full-time*	15	19%	34	44%
Working part-time**	16	21%	8	10%
Registered unemployed	0	0%	1	1%
Not registered unemployed, but seeking work	2	3%	0	0%
Long-term sick/disabled	4	5%	2	3%
At home/not seeking work	39	50%	3	4%
Fully retired (including retired early)	0	0%	2	3%
Other	2	3%	1	1%
Not applicable	0	0%	27	35%
Total	78	100%	78	100%

\* Working full-time defined as 30 hours per week or more \*\* Working part-time defined as less than 30 hours per week

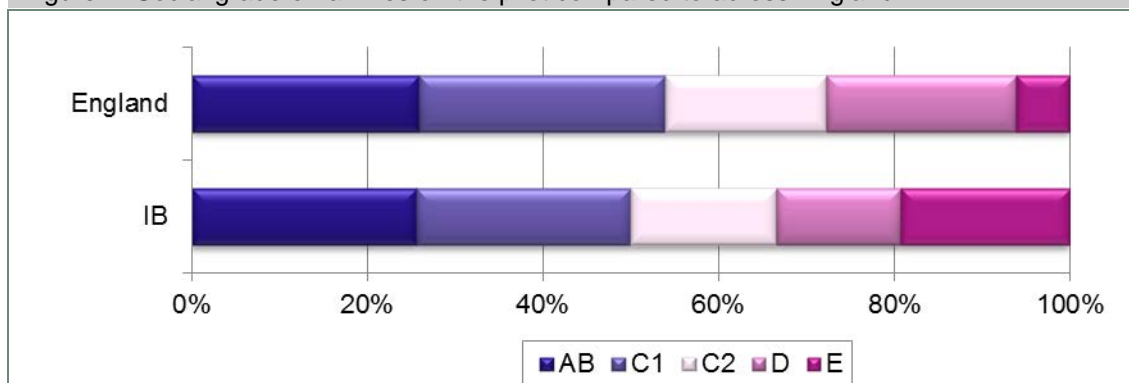
N=78

Source: SQW and Ipsos MORI Wave 3 Survey

- 2.10 There remained a good spread of responses across the social classes. Half of families were from the higher social classes (ABC1 – these grades include: upper middle class, middle class, lower middle class), while half were from the working class (grades C2DE – including: skilled working class, working class and those at the lower levels of subsistence) (Figure 1).
- 2.11 Around one fifth of participating families (19%) were categorised in social grade E, implying that the chief income earner's occupation was in casual or lower grade employment, or dependent on the welfare state. While this contrasts with the national figures where only 6% of families with dependent children fall into social grade E, it does reinforce the issues faced by families with disabled children. Indeed, the Children's Society<sup>8</sup> indicated that four in 10 disabled children live in poverty.
- 2.12 The proportion of IB families from social grade E has fallen in each wave of the survey; from 28% of families in the Wave 1 baseline survey to 19% of families in Wave 3. The section on families that have left the pilot explores this issue further.

<sup>8</sup> The Children's Society, 2011, *4 in every 10: Disabled children living in poverty*

Figure 1: Social grade of families on the pilot compared to across England



IB figures sourced from the SQW and Ipsos MORI wave 3 survey (N=78)

Figures from England sourced from Census 2001. They include the social grade of the Household Reference Person who completed the Census for families with a dependent child aged up to 18 (N=6,023,856)

Source: SQW and Ipsos MORI Wave 3 Survey, Census 2001

### Characteristics of children and young people

- 2.13 The pilot covered children and young people across the age spectrum. At Wave 3, 55% of the children and young people from surveyed families were of transition age (14-18), with four of the six sites actively targeting this group (Table 3). The proportion of young people in this group had not changed substantially from previous survey waves.

Table 3: Age band of child/young person at the time of the Wave 3 survey

Pilot site														
	1		2		3		4		5		6		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
0-5 years	0	0%	0	0%	1	10%	1	5%	3	20%	0	0%	5	6%
6-13 years	1	11%	1	7%	5	50%	12	63%	10	67%	1	9%	30	38%
14-15 years	0	0%	3	21%	2	20%	3	16%	1	7%	1	9%	10	13%
16+ years	8	89%	10	71%	2	20%	3	16%	1	7%	9	82%	33	42%

N=78

Source: SQW and Ipsos MORI Wave 3 Survey

- 2.14 Ten of the families (13%) were from the BME community (a similar proportion to the Wave 2 survey). All bar one of these families were based within two sites.

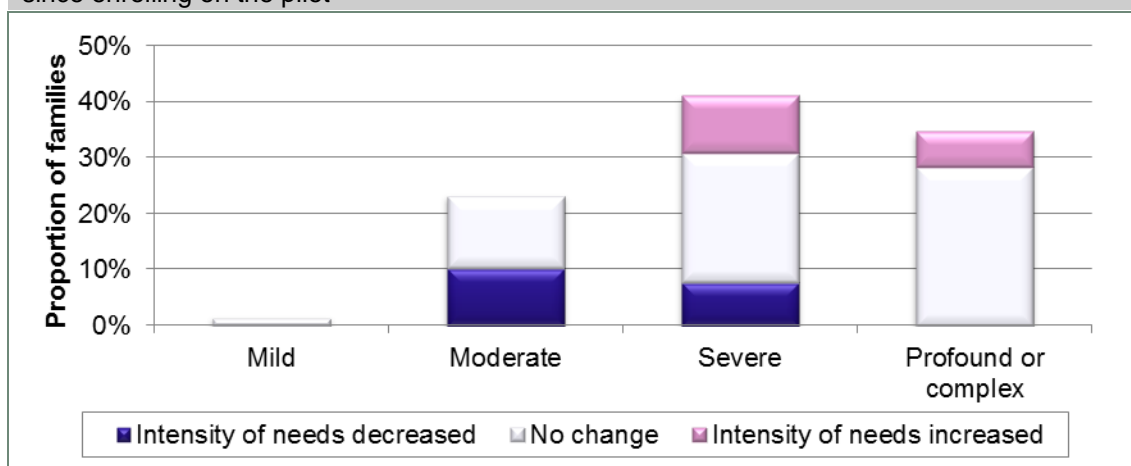
### Nature of disability

- 2.15 The pilot contained children whose lives were impacted upon severely by their condition or disability. Indeed, 76% of children and young people were reported by

their parent to have severe, profound or complex needs at the time of the Wave 3 survey (Figure 2).

- 2.16 The needs of around one third of children/young people were reported as different in the Wave 3 survey compared to the baseline survey; with the needs of 17% of the children/young person reported as more severe, while the needs of 18% were less severe. Chapter 3 will examine the extent to which these changes in need were reflected in the IB review process.

Figure 2: Intensity of child/young person's condition or disability and the change of intensity since enrolling on the pilot

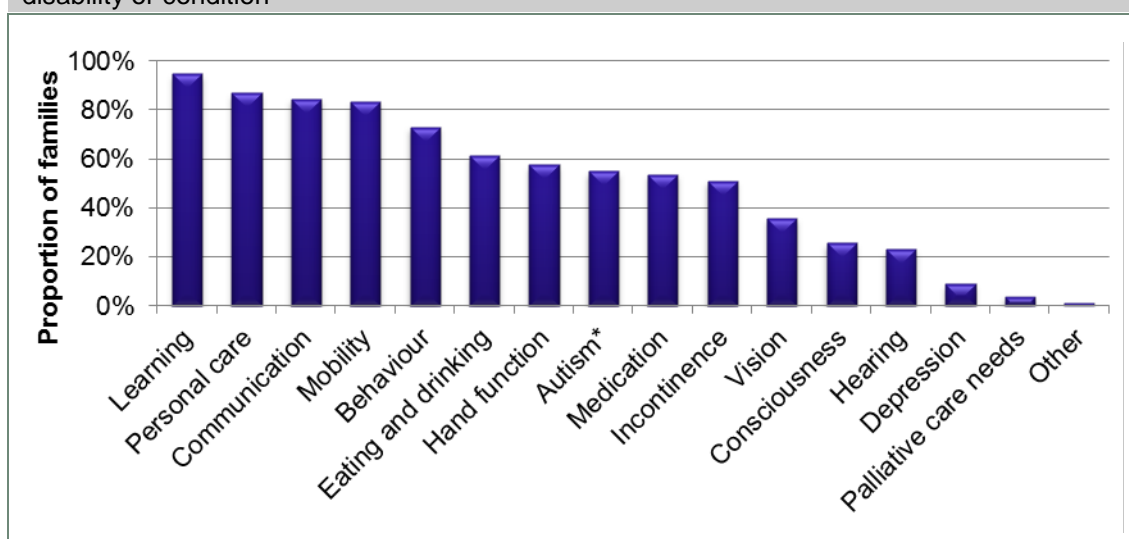


N=78

Source: SQW and Ipsos MORI Wave 3 Survey

- 2.17 Figure 3 illustrates the nature of the children's disabilities. It shows that the children/young people's conditions were most commonly demonstrated through learning difficulties (95% of children/young people were reported by their parent to be affected in this area), personal care (87%) and communication difficulties (85%).

Figure 3: Areas in which the child/young person is affected as a result of their illness, disability or condition



\* The proportion of children/young people affected by Autism includes those diagnosed with Autism, Asperger's Syndrome or Autistic Spectrum Disorder (ASD)

N=78

Source: SQW and Ipsos MORI Wave 3 Survey

### Previous use of services

- 2.18 The majority of children and young people from the evaluation cohort had accessed social care (68%), health (83%), and education provision (96%) prior to enrolling on an IB (Table 4).<sup>9</sup> The proportion of pilot families that were newcomers to the system when they joined the pilot remained similar to previous years.

Table 4: Previous experience of services and personalised approaches

Pilot site	Targeting newcomers to social care	Newcomers to social care provision		Newcomers to health provision		Newcomers to education provision		Past experience of personalisation	
		N	% of families	N	% of families	N	% of families	N	% of families
1		3	33%	2	22%	1	11%	3	33%
2		2	14%	6	43%	0	0%	6	43%
3		2	20%	1	10%	0	0%	8	80%
4		8	42%	2	11%	1	5%	8	42%
5	✓	9	60%	0	0%	0	0%	7	47%
6		1	9%	2	18%	1	9%	8	73%
Total		25	32%	13	17%	3	4%	40	51%

N=78

Source: SQW pilot monitoring returns

<sup>9</sup> It was not known whether a further 9% of families had previously accessed health provision or whether the remaining 1% had accessed education provision.

## Overview

- 2.19 Overall, **it appears that the characteristics of the families interviewed during Wave 3 were broadly similar to the achieved sample in previous years.**<sup>10</sup> Although a number of the individual families surveyed had experienced changes since enrolling on the pilot, these changes tended to balance out at the aggregate level.
- 2.20 The family survey findings have been cross-tabulated by a number of characteristics to investigate whether the results differed across families and to identify any themes. The analysis included cross-tabulations based on: pilot site; family characteristics (including marital status, social grade of chief income earner and whether child has siblings); the child/young person's age and the severity of their disability (and any change in the severity of their disability between the baseline and Wave 3); past experience of personalisation and social care provision; and changes as a result of their IB (such as the change in the size of their package compared to their traditional service provision).
- 2.21 The remaining chapters report on the main survey findings and draw attention to changes in perception across waves only where interesting and significant<sup>11</sup> differences emerged.

## Families that have left the pilot

### ***Which families have left the pilot?***

- 2.22 The remainder of this chapter examines the extent to which families left the pilot, and explores common characteristics among these families. The 2011 *Family Journey* report<sup>12</sup> provides further analysis of the reasons why families left the pilot, captured through qualitative, in-depth interviews.
- 2.23 Table 5 sets out the status in March 2012 of the 189 families who originally engaged in the pilot. Overall, 24% of families chose to leave the pilot, while a further 18% of young people moved to adult services. Two of the three sites with relatively high proportions of young people moving to adult services had targeted participants of

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<sup>10</sup> The Technical Annex provides a table which sets out key characteristics of the families surveyed in waves 1-3.

<sup>11</sup> Findings reported when significant at the 5% level. For further details on significance testing see the technical annex.

<sup>12</sup> Johnson, R., Thom, G., Prabhakar, M., 2011, *Individual budgets for families with disabled children: Final evaluation report: The family journey*

transition age, in part in the expectation that experience of an IB would assist with and after the transition to adult services.

Table 5: Status of family involvement in the pilot at end of March 2012

Table 6: Status of family involvement in the pilot at end of March 2012								
Pilot site	Still engaged in pilot		Left the pilot				Total	
			Chosen to leave the pilot		Moved to adult services			
	N	%	N	%	N	%	N	%
1	15	42%	10	28%	11	31%	36	100%
2	14	50%	3	11%	11	39%	28	100%
3	21	70%	7	23%	2	7%	30	100%
4	19	63%	9	30%	2	7%	30	100%
5	27	90%	3	10%	0	0%	30	100%
6	13	37%	14	40%	8	23%	35	100%
Total	10							
	9	58%	46	24%	34	18%	189	100%

*N=189*

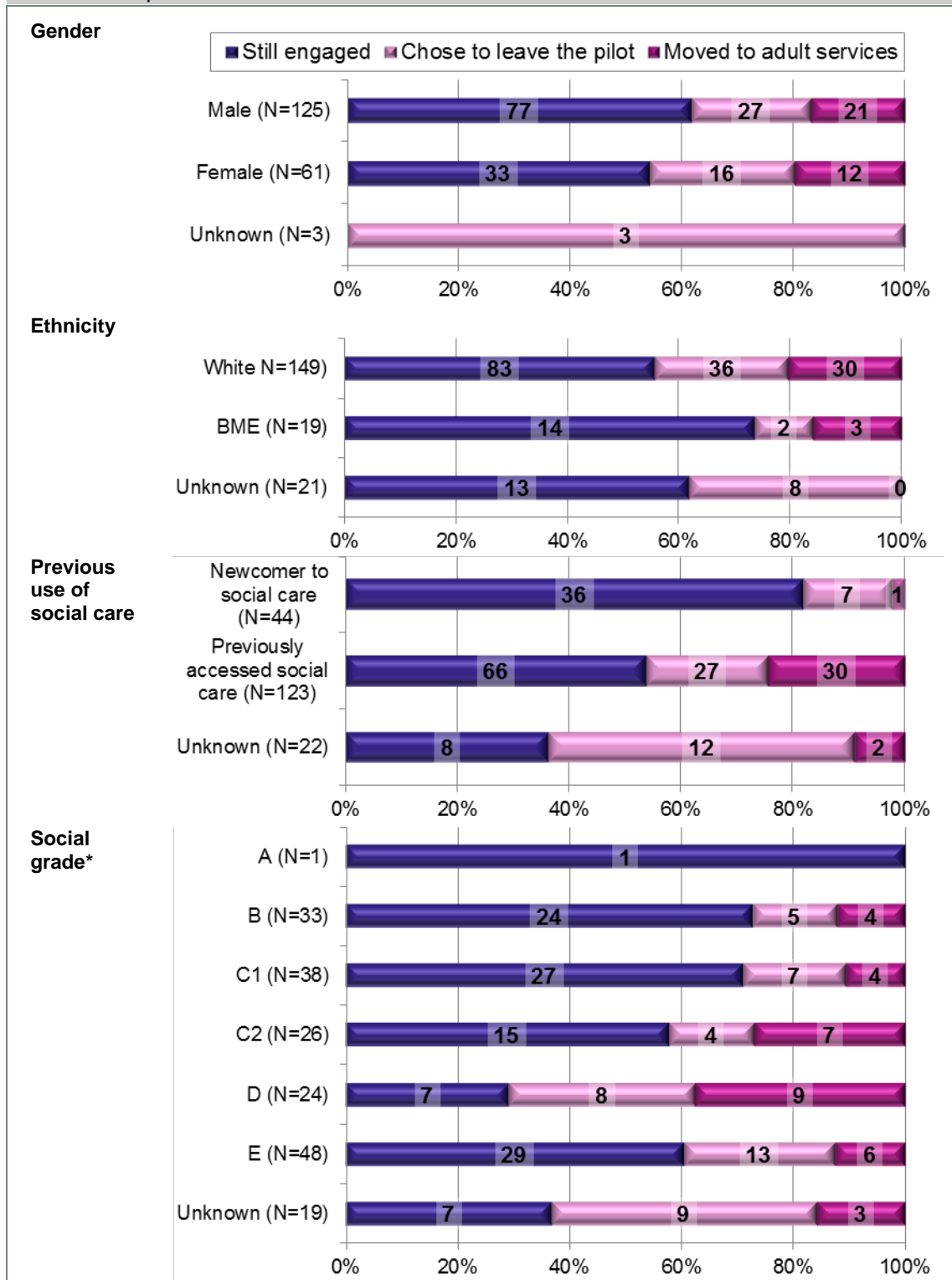
*Source: SQW pilot monitoring returns*

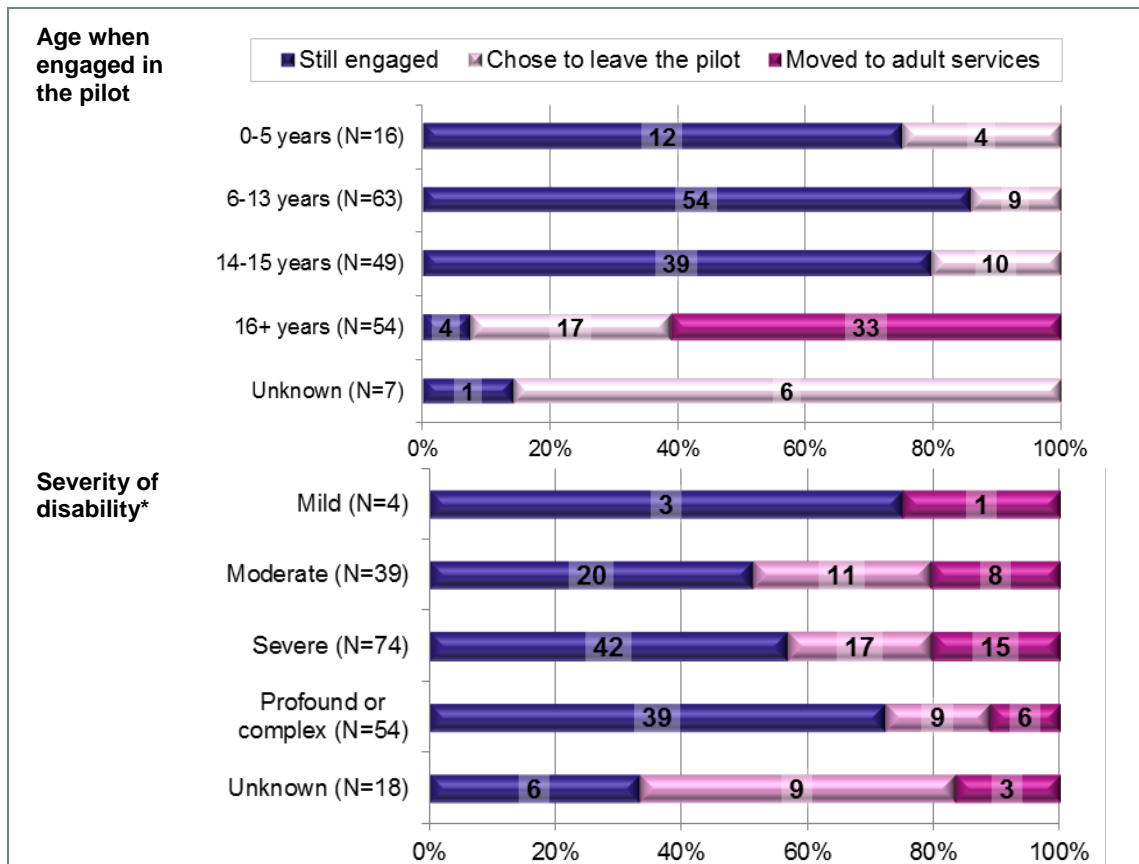
2.24 It appears that:

- **Newcomers to the system were more likely to remain engaged in the process** than those who had previously accessed social care, perhaps because of their lack of experience of traditional service provision, or because in a small number of cases these families fell below the traditional social care threshold (as was identified in the previous reports)
- **Almost three quarters of families with profound or complex needs at the start of the pilot were still engaged at the end of March 2012, compared to 58% of all those families who signed up.** Larger budgets tend to indicate more complex needs, so families whose children had profound or complex needs might have had more scope/ self-interest to vary their provision through IB
- Families from lower social grades were more likely to choose to leave the pilot than those from higher social grades.
- As would be expected, most of the young people aged 16+ at the time of the baseline survey have since moved to adult services (Figure 4).



Figure 4: Characteristics of children/young people at the outset of the pilot, by whether they have left the pilot





\* At the time of the Wave 1 survey

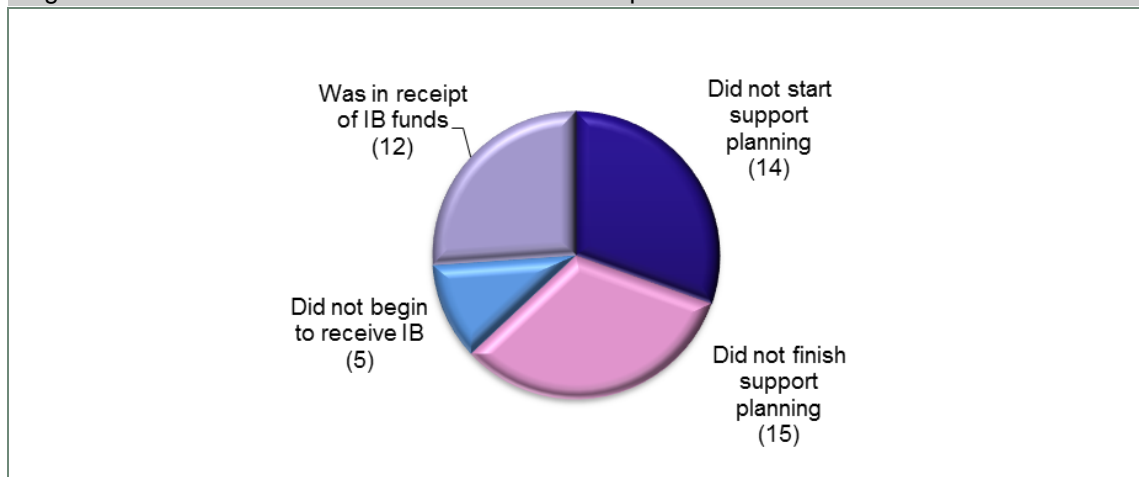
N=189

Source: SQW pilot monitoring returns and SQW and Ipsos MORI Wave 1 Survey

### At what point do families leave the pilot?

- 2.25 Families most commonly chose to leave the pilot before finishing support planning (in 63% of cases), although in just over a quarter of cases (26%) the families left once they were in receipt of their IB (Figure 5).

Figure 5: Point at which families chose to leave the pilot



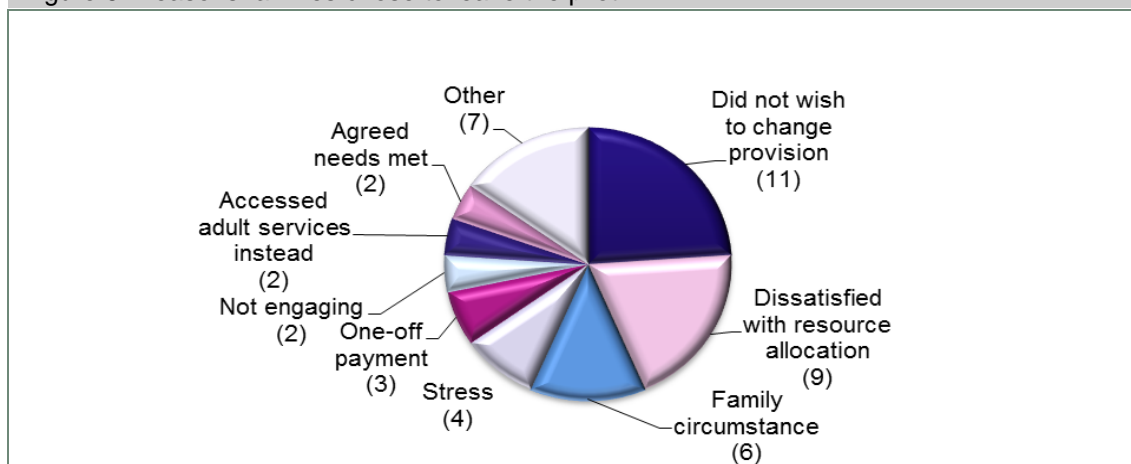
N=46

Source: SQW pilot monitoring returns

**Why did families chose to leave the pilot?**

- 2.26 **Most families that chose to leave the pilot did so prior to receipt of an IB.** The most common reasons families left the pilot were that they did not wish to change their current provision (in 24% of cases) (Figure 6). As such, it would seem that these families entered the pilot wanting to change, or at least explore changing their provision. However, on considering what could be changed they decided that the different offer was not sufficiently attractive for them to take up an IB.
- 2.27 A further 20% left because they were dissatisfied with their resource allocation. One site in particular had experienced a number of families (5) choosing to leave the pilot as a result of their indicative budget allocation coming out lower than their traditional service allocation. However, the learning shared by this site led other sites to handle this issue more sensitively and therefore minimised drop out in other cases.

Figure 6: Reasons families chose to leave the pilot



N=46

Source: SQW pilot monitoring returns

- 2.28 A small proportion (8%) of families who started to receive an IB chose to leave the pilot. These families chose to leave for different reasons, but these tended to relate to no longer requiring the support, rather than dissatisfaction with their IB. A quarter of these families (3) received one-off IB payments, while a further four families left the pilot because their needs were met and they no longer required support through their IB. Another reason for leaving the pilot once in receipt of their IB was that the family had moved out of the area.

## Summary

2.29 Table 6 provides a summary of the findings from this chapter.

Table 6: Summary of findings

The original cohort consisted of 189 families engaged in the pilot by March 2010. Of these, 173 (92%) completed the 2010 baseline survey, 126 (67%) also completed the 2011 Wave 2 survey and 78 (41%) also completed the 2012 Wave 3 survey.

The characteristics of families still engaged at Wave 3 were broadly in line (proportionately) with the original cohort.

Certain groups (existing social care users, families from lower social grades, young people aged 16+ at baseline and those with lower level needs) were more likely to leave the pilot; either through choice or transition into adult services.

Families most commonly left the pilot before finishing support planning. A small number of families did drop out once in receipt of their IB – but this tended to be because they no longer required support, rather than that they were dissatisfied with their IB.

## 3: The IB review process

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### Introduction

- 3.1 This section discusses the IB review process that families from the original cohort have been through. It draws on findings from the site case studies, the site monitoring data and the responses of 77 respondents to the Wave 3 family survey that had been through at least one review process.

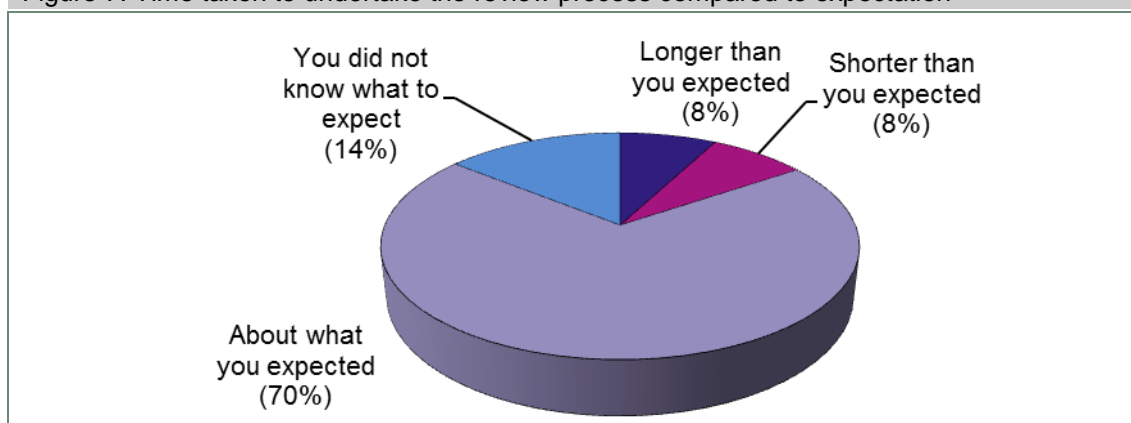
### The review process

- 3.2 The 77 families have, at least, taken part in formal 6 monthly reviews since receipt of their funding. This review process has in some cases been brought forward for example, if families have experienced a significant change in circumstance and therefore required changes to their support plans, or in cases where families had struggled to manage their budgets and therefore needed more frequent reviews to ensure the funding was being spent appropriately. In addition, the formal review process was also complemented by more regular and informal contact through either the lead professional or social worker.
- 3.3 The formal review process was undertaken as a face to face meeting and attended by at least the family (and child/young person where appropriate) and the lead professional and/or social worker. Two of the sites sought to align the IB review process with their statutory review processes and therefore also included relevant education and health professionals at the meetings and in one of the cases an independent chair. Another area sought to include the relevant personal assistants, as they were felt to have an important contribution to make to the meeting.
- 3.4 An emphasis was placed on the relevant lead professional or social worker to prepare for the review meeting. In one site, this involved the dissemination of a self-assessment questionnaire to both providers/personal assistants and families to understand whether both parties felt the relevant outcomes had been achieved and if not, why. This exercise was felt to provide useful information to inform the review, which was undertaken following receipt of the completed questionnaires.
- 3.5 The focus of each of the review processes was to understand the extent to which the outcomes specified in the family support plan had been achieved and what had worked well/worked less well in terms of service/support provision. This included

looking forward to the next six months/year to assess whether the outcomes and existing provision would remain relevant and appropriate. Resource allocation was in general only reviewed in cases where families had experienced a specific change in circumstance.

- 3.6 Families reported that reviews took, on average, six hours to complete. This estimate is higher than the one provided by sites, perhaps reflecting the preparatory work undertaken by families. There was considerable variation around the average. For instance, 56% of the reviews were completed within two hours, while for 10% of families the review process took in excess of 15 hours. In most cases (70%) the review process took about as long as expected (Figure 7).

Figure 7: Time taken to undertake the review process compared to expectation



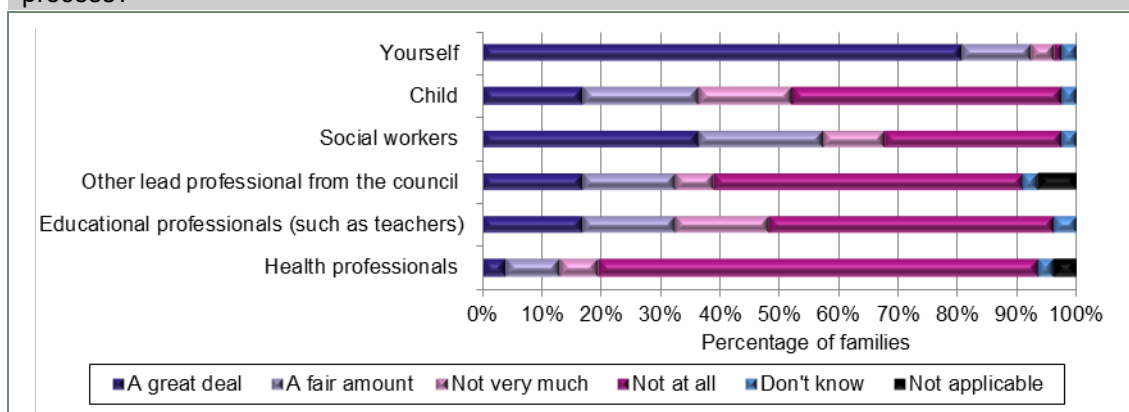
N=77

Source: SQW and Ipsos MORI Wave 3 survey

### ***Involvement of different parties in the review process***

- 3.7 Parents reported that the review process most commonly involved:
- The parent (involved 'a great deal' or 'fair amount' in 92% of reviews)
  - Social worker (57%)
  - Child/young person (36%), often related to the particular age and capacity of the young person
  - Education professional – e.g. teacher (32%)
  - Other lead professional from the council (32%).
- 3.8 Health professionals were perceived to have been involved a great deal or fair amount in 13% of review processes (Figure 8).

Figure 8: To what extent, if at all, did the following people contribute to the last review process?



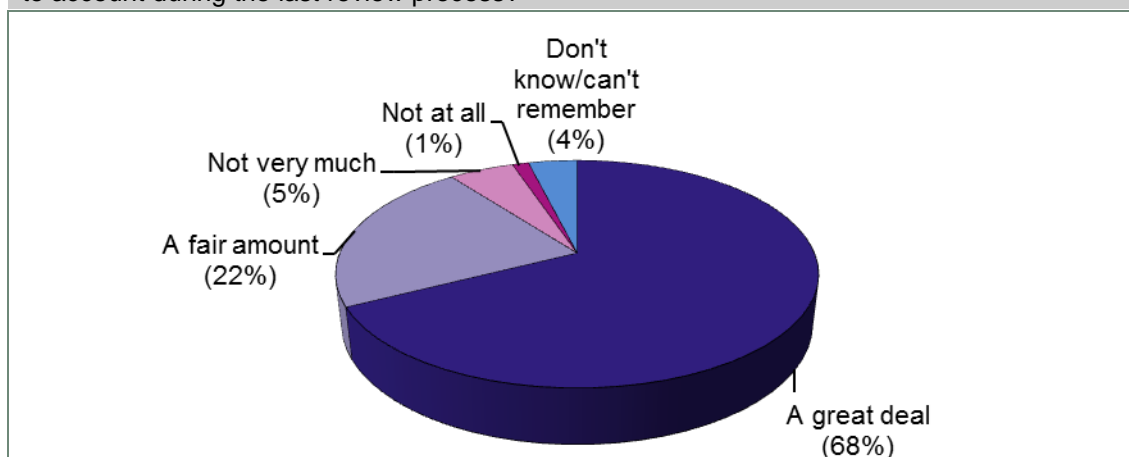
N=77

Source: SQW and Ipsos MORI Wave 3 survey

### ***Involvement of families in the review process***

- 3.9 The majority of families (90%) felt that the views of themselves and their family were taken into account during the last review process – including 68% who reported that their views were taken into account ‘a great deal’ (Figure 9). Social workers perceived the IB review process to be more inclusive, supportive and person centred than before and ‘much more positive’ than other types of review; focusing on whether the support plan was meeting those outcomes that it set out to achieve, and what was working and not working, rather than on other specifics (such as medication).
- 3.10 Within the families in this sample, young people aged 16 or over at Wave 3 were more likely than average to have had ‘a great deal’ of involvement in the review meeting. Almost one third (31%) of young people aged 16+ had a great deal of involvement, compared to 17% of all children/young people.

Figure 9: To what extent, if at all, do you think that you and your family’s views were taken in to account during the last review process?

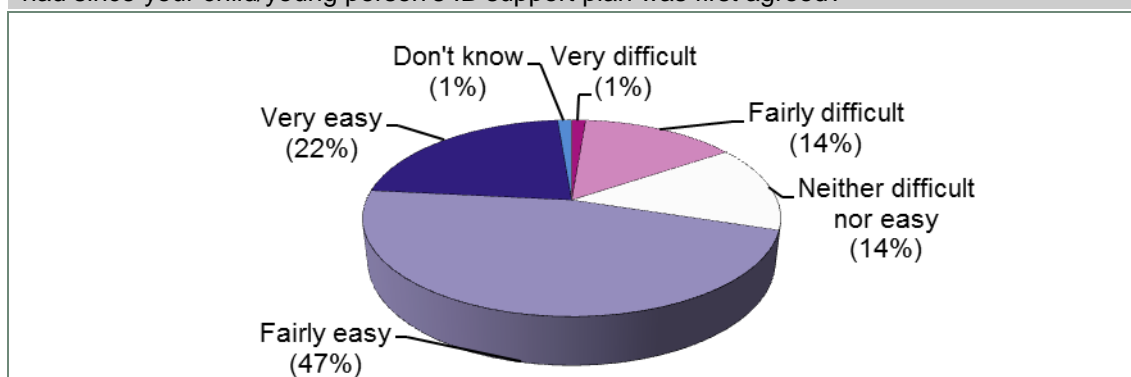


N=77

Source: SQW and Ipsos MORI Wave 3 survey

- 3.11 Over two thirds of families that had been through at least one review felt the process was 'very' or 'fairly easy', while 15% felt it had been difficult (Figure 10). Existing service users were more likely than newcomers to the social care system to report that the review process had been easy (78% of existing users found the review process easy compared to 56% of newcomers), perhaps reflecting learning through previous experiences.

Figure 10: Overall, how easy or difficult did you find the process for all the reviews you have had since your child/young person's IB support plan was first agreed?

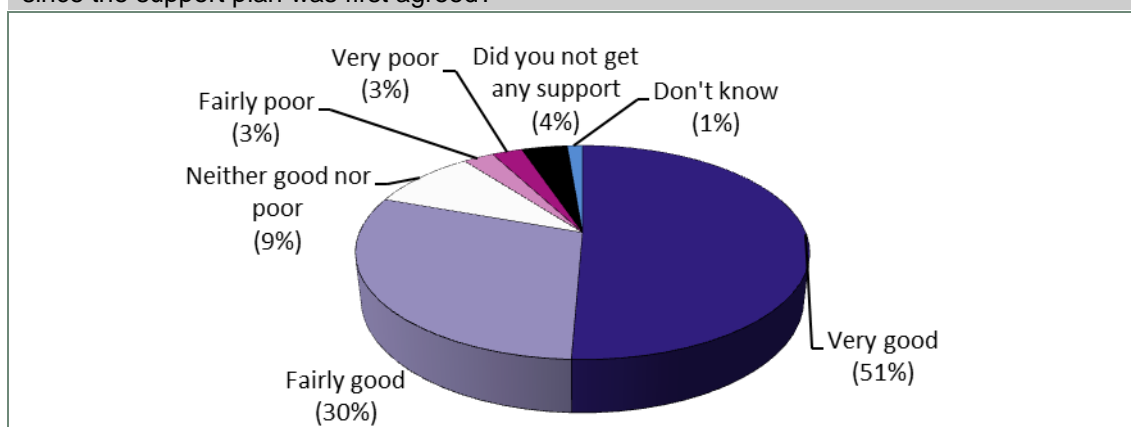


N=77

Source: SQW and Ipsos MORI Wave 3 survey

- 3.12 The majority of families also rated the support they received for their reviews as fairly or very good (Figure 11). Perceptions of the support staff were key to parental satisfaction with the support received. Where staff were perceived to be positive, responsive and easy to contact parents tended to be happy with the support received, while dissatisfaction with review staff resulted in a small number of families rating the support received at reviews as poor.

Figure 11: How would you rate the support that you received for all the reviews you have had since the support plan was first agreed?



N=77

Source: SQW and Ipsos MORI Wave 3 survey



## Outcomes from the review

### ***Changes resulting from the reviews***

- 3.13 **Almost half of families consulted had experienced changes in their budget allocation (40%) and/or support or services used (46%) since their first IB support plan was agreed** (Figure 13). Of the 36 families whose services or support had changed one third perceived the support plan to have changed ‘a lot’, while 56% felt it had changed ‘a little’ and 11% felt their support plan had not noticeably changed. Some families also reported gaining ideas from other families in relation to how they used their IB funding, and becoming more confident suggesting different types of support/services.
- 3.14 The most common changes in service provision were increases *and* decreases to provision of personal assistants and short breaks. On balance, the use of personal assistants appears to have increased and the use of short breaks decreased. This follows substantial increases in the use of personal assistants and short breaks in the initial IB packages compared to traditional service provision, as identified in the previous report.
- 3.15 The site case studies provided a similar picture of review meetings leading to changes in packages. Such changes were often small and reflect changing needs of the family, or in some cases families were reported to be becoming more creative in the use of their IB as they became more experienced. Some examples of the changes made are set out in Figure 12.

**Figure 12: Examples of changes in support following review**

One family had a plan with a lot of flexibility in it – relating to timing of PA visits/activities etc. This hadn't proved suitable for the young person with autism and so was revised to be more structured.

A parent who had been managing the budget was unable to do so for mental health reasons, and the social worker agreed that the aunt manage the budget for a specified period.

A child had outgrown services and expressed a desire to change to alternative provision.

Review process tended to involve ‘tweaking’ provision to ensure provision still met needs, and the support plans were updated where necessary to reflect changes in outcomes and support required. Such tweaks sometimes reflected changes in the child's needs, or wider changes such as parental separation.

One young person had a brain injury and had been ill which meant that their budget was not fully utilised as originally planned. Also, they needed more health funding than was in the plan.

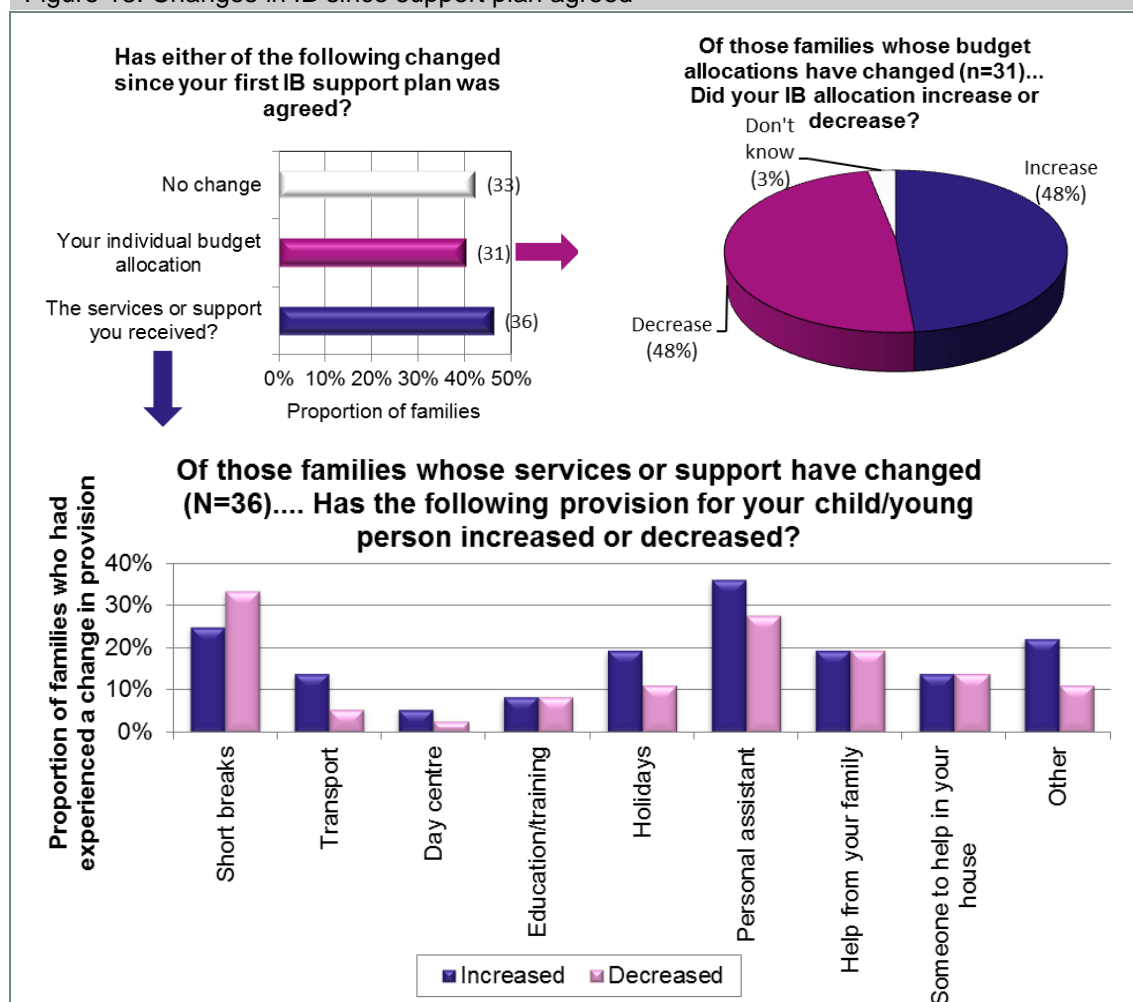
One young person just moved on to Adult Care and was entitled to a higher amount of support for personal care. Their support plan had increased in anticipation of this transition.

There were a couple of instances where a provider got one young person home earlier from residential care and the young person wanted change their provider as they wanted residential weekend care instead.

*Source: SQW through case study research*

- 3.16 The review also considered how well the family was managing their budget. In two areas cases were reported of families struggling to manage the budget: some struggled with the maths while others did not review what they were spending against the amount set. The review provided an opportunity to talk through and suggest alternative approaches to managing the budget.
- 3.17 Equal numbers had increased or decreased their budget. A small number of families provided reasons for these changes in budget: including cases where there had been changes in family circumstances; new education/health funding had become available; or old funding was no longer available to them through the IB. The nature of these changes reflects that the sites did not seek to revisit the RAS assessment again at the point of review, rather to check how well the package was working

Figure 13: Changes in IB since support plan agreed



Note: When asked whether the following had changed since their first IB support plan was agreed, families were able to report changes in one or both of 'their individual budget allocation' and 'services or support received', or they were able to report that there had been no change in either.

N=77

Source: SQW and Ipsos MORI Wave 3 survey

- 3.18 Initial IB package costs ranged from £240 to £42,579 per annum across the sites for those individuals still in receipt of an IB (Table 7). Average package costs rose from £7,382 to £8,855 following review, with an average increase of £1,473.
- 3.19 However, there was a lot of variation around this average. Just over two fifths of families did not experience a change in package through their reviews (Table 8), and in all, 82% of families had experienced a fairly small change (of less than £3,600, half the original average budget).
- 3.20 Yet in some cases, package costs were revised dramatically at review. The largest changes in budget have been increases rather than decreases; five families had increases in their budget of more than £11,000. The most common reasons for packages being revised upward by more than 100%, were:
- Change in young person's needs/worsening of their health (in 7 cases this was a reason for increased provision)
  - Additional funding sources to meet needs, such as funding from health, education and the Raising Participation Age pilot (4 cases).

Table 7: IB package costs before and after reviews<sup>13</sup>

Pilot site	Number of families	Range of initial IB package costs	Average initial IB package cost	Range of IB package costs following review	Average IB package cost following review
1	11	£3,055 to £12,155	£6,434	£3,055 to £12,155	£6,779
2	14	£240 to £24,752	£5,496	£800 to £55,608	£10,027
3	17	£5,000 to £13,715	£8,984	£5,000 to £32,000	£11,918
4	15	£1,553 to £17,597	£7,441	£780 to £19,461	£7,467
5	25	£722 to £4,644	£2,132	£683 to £3,686	£1,709
6	13	£1,126 to £42,579	£18,147	£2,492 to £45,704	£20,686
<b>All sites</b>	<b>95</b>	<b>£240 to £42,579</b>	<b>£7,382</b>	<b>£683 to £55,608</b>	<b>£8,855</b>

*N=95, Excludes children/young people that have dropped out of the pilot or moved into adult social care. Also excludes cases where package costs were not available. Source: SQW pilot monitoring returns*

<sup>13</sup> Post review figures from most recent review.

Table 8: Changes in IB packages following reviews

	Number of families	Percent of families
<b>Change in IB package</b>		
More than £3650 decrease in IB package	1	1%
£1-3650 decrease	26	27%
No change	40	42%
£1-3650 increase	16	17%
£3651-£11000 increase	7	7%
More than £11000 increase	5	5%
<b>Percentage change in IB package</b>		
More than 50% decrease in size of IB package	4	4%
Less than 50% decrease	23	24%
No change	40	42%
Less than 50% increase	15	16%
More than 50% increase	13	14%

*N=95, Excludes children/young people that have dropped out of the pilot or moved into adult social care. Also excludes cases where package costs were not available.*

*Source: SQW pilot monitoring returns*

## Summary

3.21 Table 9 summarises the key findings from this chapter.

Table 9: Summary of findings

The review process has tended to check that the agreed support plan was working as intended to achieve the agreed outcomes, rather than to revisit the assessment or resource allocation.

A number of budgets changed at review, usually due to changing needs / circumstances. However, in the vast majority of cases the changes in the budgets were fairly small.

The majority of families felt that the views of themselves and their family were taken into account during the last review process. Social workers also perceived the IB review process to be more inclusive, supportive and person centred than before and 'much more positive' than other types of review.

The most common changes in service provision were increases *and* decreases to provision of personal assistants and short breaks. On balance, the use of personal assistants appears to have increased and the use of short breaks decreased.

Such changes were often small and reflect changing needs of the family, or in some cases families were reported to be becoming more creative in the use of their IB as they became more experienced.

## 4: Outcomes achieved by the original cohort of participating families

### Introduction

- 4.1 This chapter examines the outcomes achieved by disabled child/young person and their families following receipt of an IB. It is based largely on findings from the family surveys, augmented by feedback through the child/young person surveys.
- 4.2 The evaluation tested the hypothesis that IBs would lead to increased outcomes (such as choice and control and improved quality and appropriateness of care), which would in turn lead to improved impacts. The key parts of the evaluation framework are set out in Table 10. This chapter examines the extent to which families have reported improvements in outcomes, by comparing Wave 3 survey responses to the position at baseline. The next chapter then discusses the extent to which longer term impacts have been identified.

Table 10: Family related outcomes and impacts framework

Table 10.1 Family-related outcomes and impacts framework					
	Disabled Child/Young Person outcomes/impacts		Theme		Family-based outcomes/impacts
OUTCOMES	Increased user satisfaction with service provision		INCREASED CHOICE AND CONTROL		Increased user satisfaction with service provision
	Increased control over daily life	←		→	Increased control over daily life
	Increased personal costs e.g. increased responsibility				Increased responsibility of coordination/personal costs
	Improved access to more appropriate services		QUALITY AND APPROPRIATENESS OF CARE		Improved access to more appropriate services
Greater continuity of care	←	→		Greater continuity of care	
Improved quality of care				Improved quality of care	
Fewer unmet needs				Fewer unmet needs	
↓					
IMPACTS	Improved health (self-perceived)		BE HEALTHY		Improved health (self-perceived)
	Increased user satisfaction with service provision	←		→	Reduction in family stress levels
					Increased user satisfaction with service provision
	Increased sense of safety when undertaking activities both inside and outside of the home	←	STAY SAFE	→	Reduced anxiety associated with child undertaking activities inside and outside of the home
	Increased enjoyment of learning/school	←	ENJOY AND ACHIEVE	→	Increased labour market participation
	Improved educational attainment				Improved educational attainment of siblings

Disabled Child/Young Person outcomes/impacts	Theme	Family-based outcomes/impacts
Increased self confidence Increased independence Increased social engagement and participation in the community	← <b>MAKING A POSITIVE CONTRIBUTION</b> →	Increased parental confidence
Increased range of social and economic opportunities available Improved quality of life Increased labour market participation or engagement in non-compulsory education (for children in transition)	← <b>ACHIEVE ECONOMIC WELL BEING</b> →	Wider range of social and economic opportunities available Improved quality of life Strengthened family units Increased labour market participation or engagement in non-compulsory education (for children in transition)

*Note: Content that relates to impacts is greyed out and is discussed in the next chapter.*

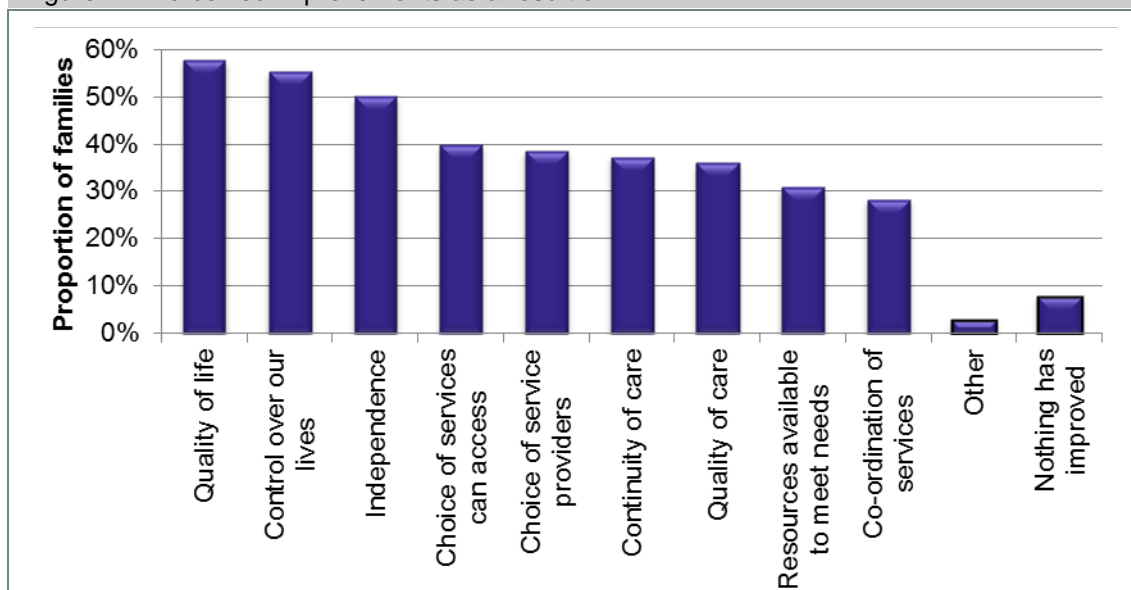
Source: SQW Individual Budgets Evaluation Briefing Note at

<http://www.education.gov.uk/childrenandyoungpeople/sen/ahdc/a0068208/ahdc-individual-budgets>

## Family impressions of change

- 4.3 The majority of families (58%) perceived, at the time of the survey and asking them to think back, that their quality of life had improved as a result of their child's IB (Figure 14). Over half of families (55%) reported an increase in control over their lives, and half reported increased independence as a result of the IB. A smaller proportion of families stated that there had been other outcome improvements; relating to increased choice and coordination of services and improved quality of care.
- 4.4 Families where the child/young person had impaired mobility and those whose IB funding allocation was more than twice as great as their traditional package (11 cases) were more likely to report improvements in their independence as a result of their IB than the average respondent.
- 4.5 Families whose IB funding allocation was greater than their traditional package were also more likely to report improvements in control over their lives at Wave 3.

Figure 14: Perceived improvements as a result of IB



N=78

Source: SQW and Ipsos MORI Wave 3 survey

- 4.6 This analysis is based upon responses to a single question in the Wave 3 survey, which asked parents which areas, if any, had improved as a result of their IB. In Control used a similar 'retrospective' approach to measuring outcomes from self directed support and IBs. They also found a perceived improvement in quality of life: with 73% of the 47 family respondents reporting that the self directed support and IB had 'helped' or 'helped a lot' with their quality of life.<sup>14</sup> This statistic is somewhat higher than the 55% of IB pilot families who reported an improvement – the difference possibly due to the self-selection of the In Control sample.
- 4.7 However, there is an inherent methodological risk associated with this retrospective approach in that it requires families to think back to prior to their IB (in our case two years or so) in order to judge whether aspects have improved. So, while these results are fairly encouraging, the remainder of the analysis looks at family perceptions now (at Wave 3) compared to what they actually reported in previous waves of the survey. This 'before and after' approach provides more robust data as people are asked to comment each time on how they feel at that moment, and so it avoids any issues of memory recall.

<sup>14</sup> Crosby, N. 2010, *Personalisation: Children, young people and families: Briefing 3 Evaluation and Outcomes*

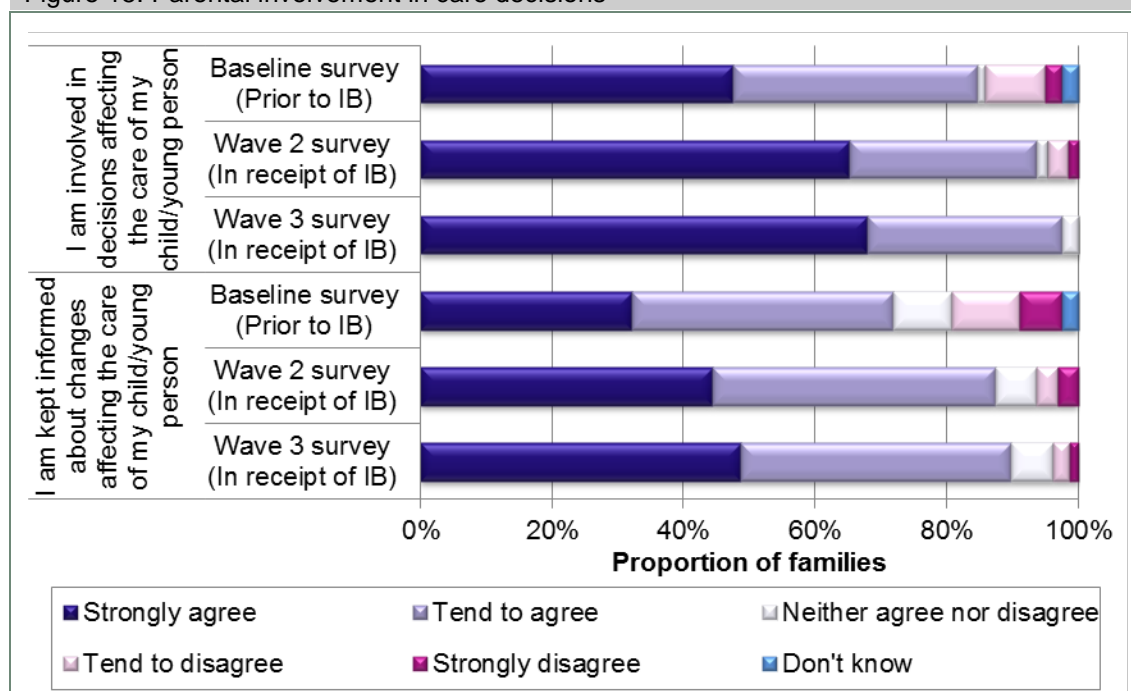
## Increased choice and control

### ***Involvement in the process***

- 4.8 Prior to enrolling on an IB, the majority of parents already perceived themselves to have relatively high levels of involvement in the process. Almost three quarters of families (72%) either 'strongly' or 'tended to agree' that they were kept informed of the decisions that affected their children/young people, while 85% felt that they were involved in the decisions that affected their children/young people prior to enrolling on the pilot (Figure 15).
- 4.9 Despite starting from this relatively high base, comparing these 'baseline' responses with post IB responses from the Wave 2 and Wave 3 survey suggests that **the IB has increased perceived levels of control over provision for some families**. Indeed, 32% of responding parents and carers reported having a higher level of involvement in decisions affecting the care of their child/young person by Wave 2 (compared to the baseline). By contrast, 10% reported feeling less involved and 58% reported no change at Wave 2. Therefore, overall there was a net change of +22% between baseline and Wave 2, indicating a considerable level of improvement, even from a high base.
- 4.10 Figures from the Wave 3 survey indicate that involvement in decision making improved very slightly, with a net improvement of +27% from the baseline. A Wilcoxon Signed Ranks Test on the responses from all families showed there to be a statistically significant improvement between the baseline and Wave 3 responses.
- 4.11 Perceptions of the extent to which parents were kept informed saw a similar net improvement from the baseline survey to the Wave 2 survey of +30%. This net improvement was largely sustained at the time of the Wave 3 survey (+24% improvement from baseline, which was associated with a statistically significant overall improvement).



Figure 15: Parental involvement in care decisions

N=78<sup>15</sup>

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

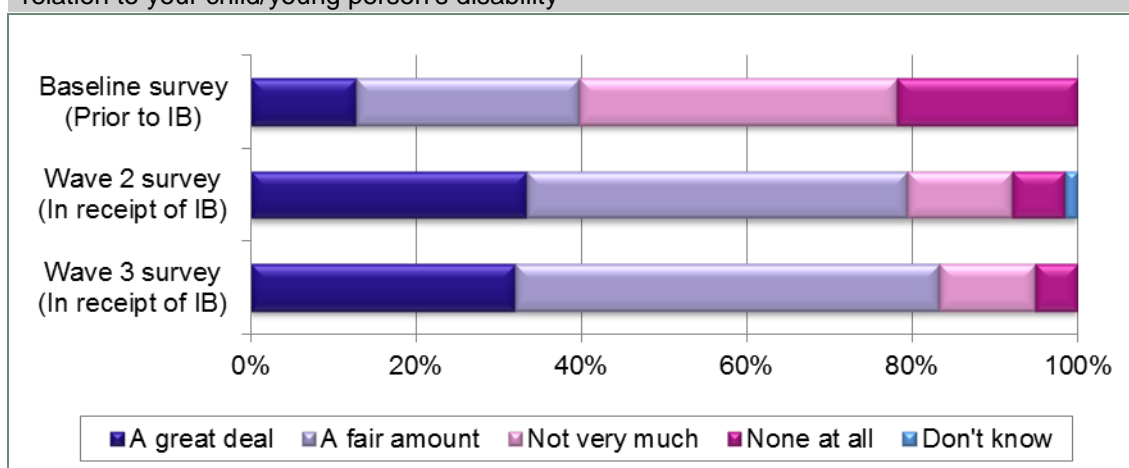
### Choice and control over services

- 4.12 **The majority of families have experienced an increase in their control** over the help they receive in relation to their child/young person's disability since the baseline survey (Figure 16). At the time of the Wave 2 survey 64% of responding parents who were in receipt of their IB reported having more control over the help they received, while 6% reported they had less control than at the baseline and 30% reported no change – a net improvement of +57%<sup>16</sup>. The net change reported through the Wave 3 survey was similar at +54% (which was associated with a statistically significant overall improvement).
- 4.13 Over three quarters (83%) of the 47 parents who reported having 'not much' or 'none at all' control over the help they received prior to IB, reported having 'a fair amount' or 'great deal' of control by Wave 3.

<sup>15</sup> When presenting responses to 'before and after' outcome and impact questions across survey waves, Wave 2 and 3 figures only include responses from families who were in receipt of their IB by the time of that particular survey, and who went on to complete the Wave 3 survey (63 families in Wave 2 and 78 families in Wave 3). At Wave 2 a number of families were still going through the support planning process and thus were considered to be too early in the process to be able to comment on the outcomes and impacts of the pilot.

<sup>16</sup> The percentages are subject to rounding.

Figure 16: How much control, if any, do you feel you have over the help you receive in relation to your child/young person's disability

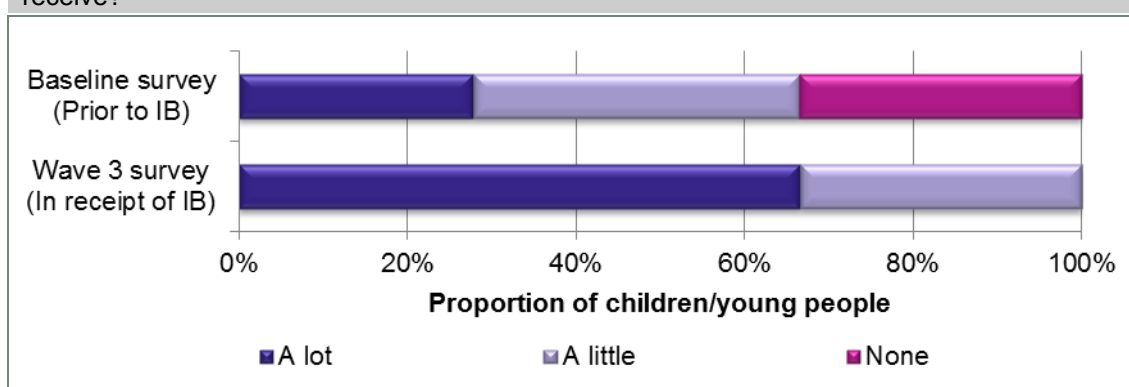


N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

- 4.14 The responses highlighted a link between families' perceived control over their support and their ability to support family members. Within the families in this sample, those who felt less in control of the help that they received in relation to their child's disability at Wave 3 were more likely to report that at times they found it difficult to provide others in the household with the support they needed.
- 4.15 Children and young people also experienced an increase in control over their provision. From a baseline position where 5 of the 18 children surveyed felt there was 'a very big problem' around 'staff in services not telling you about changes that affect you', only one felt it was 'a fairly big problem' by Wave 3. Moreover the number reporting 'a lot' of say over the services they received more than doubled (Figure 17).

Figure 17: How much say do you think you personally have in deciding what services you receive?



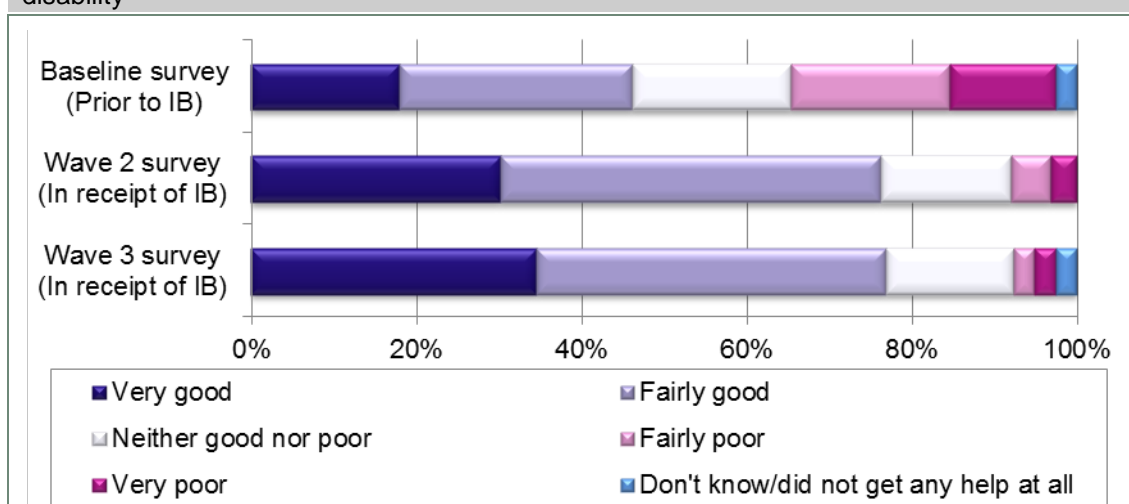
N=18

Source: SQW and Ipsos MORI Wave 3 survey

### Satisfaction with services

- 4.16 Around three quarters of parents (77%) rated the help they received as ‘fairly’ or ‘very good’ at Wave 3 (Figure 18). Since enrolling on the pilot and completing the baseline survey, parent perceptions of the help received in relation to their child/young person have undergone a marked change (Figure 18). By the Wave 2 survey, 56% of parents rated the help they received as better than at baseline, while 13% rated the help they received worse and 31% rated it the same – a net improvement of +43%. The level of net improvement has been maintained during the latest year (+45% improvement since baseline, and was associated with a statistically significant overall improvement).
- 4.17 **One fifth (19%) of families went from being unhappy with the help received prior to the pilot, to perceiving their support as ‘fairly’ or ‘very good’ at Wave 3** – a positive change, while only 4% of families viewed help as poor both before and after enrolling on the pilot.

Figure 18: How would you rate the help you receive in relation to your child/young person's disability



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

- 4.18 Over four fifths (82%) of the families which were satisfied with the pilot rated the help they received as ‘fairly’ or ‘very good’ at Wave 3, compared to only 43% of families that were dissatisfied with the pilot.

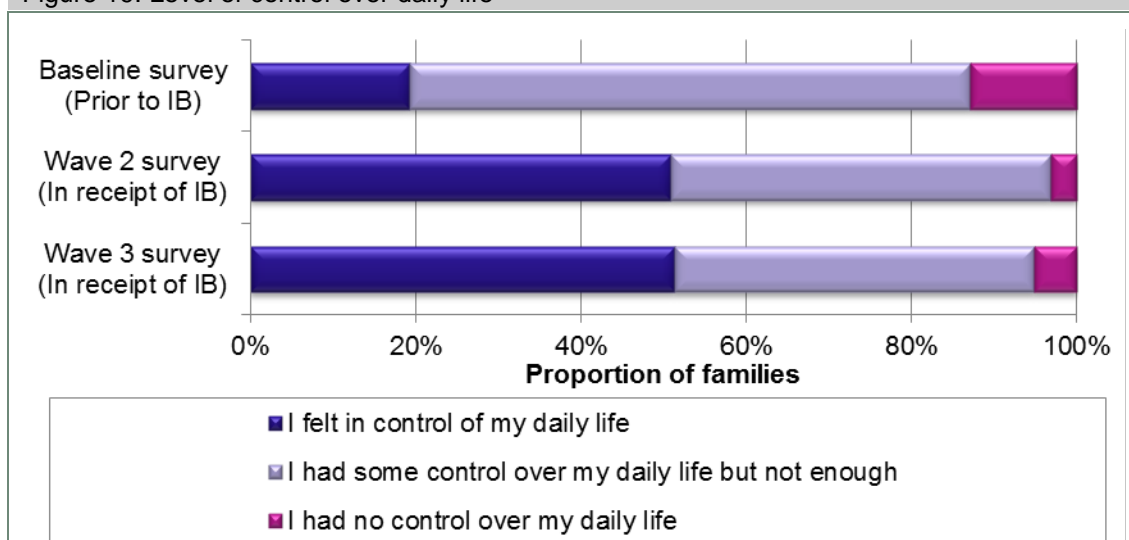
### Increased control over daily life

- 4.19 Almost half of families experienced an improvement in control over their daily lives after enrolling on the pilot (Figure 19). Forty-three percent of parents in receipt of an

IB reported more control over their daily lives at Wave 2 than in the baseline survey, while 6% reported less control (51% reported no change) - a net improvement of +37%. This net improvement in control over daily life remained broadly similar at Wave 3, at +35% (which was statistically significant).

- 4.20 **Improvements in control over daily life were most commonly reported by families who prior to the pilot had low levels of control over their lives.** Almost all (9) of the 10 families who had no control over their daily life at the baseline experienced some level of improvement in control by Wave 3, while half of the 53 families with some level of control over their daily experienced an improvement in control over the course of the pilot.
- 4.21 Existing users were more likely than newcomers to the system to report that they ‘felt in control of [their] daily lives’ and more likely to rate the help they received in relation to their child/young person’s disability as good at Wave 3. The extent to which certain groups (like existing service users) benefited more from IB than others is explored in ‘*Distribution of Outcomes*’ later in this chapter.

Figure 19: Level of control over daily life



N=78

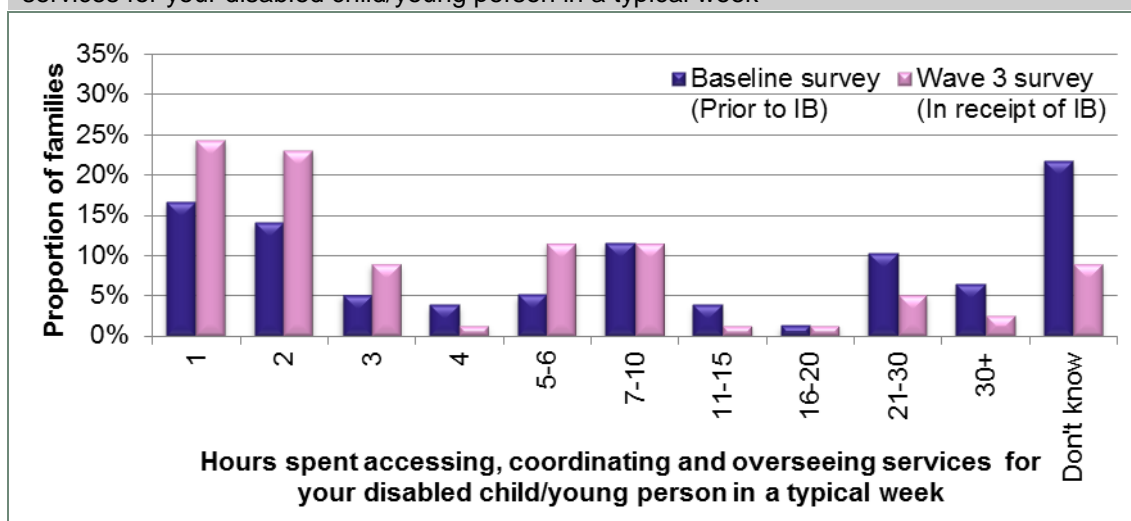
Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

#### ***Time spent accessing, coordinating and overseeing services***

- 4.22 The median length of time spent (both prior to the IB and since families became in receipt of their IB) was 2 hours per week, although there was considerable variation in time spent (Figure 20). This suggests that **managing an IB involves a similar time commitment to the management of standard services.**

- 4.23 That said there was a fair amount of individual level change. The majority (82%) of families who spent 5 or more hours coordinating services per week at the baseline reported spending less time coordinating their IB services at Wave 3; often less than half the amount of time previously reported. This suggests that in cases where service coordination involved considerable time investment prior to the IB, the IB made a positive difference to the time required to coordinate provision. Conversely, where there was less resource involved / the family spent less time prior to the IB, the amount of time required actually rose slightly.

Figure 20: Roughly how many hours do you spend accessing, co-ordinating and overseeing services for your disabled child/young person in a typical week



N=78

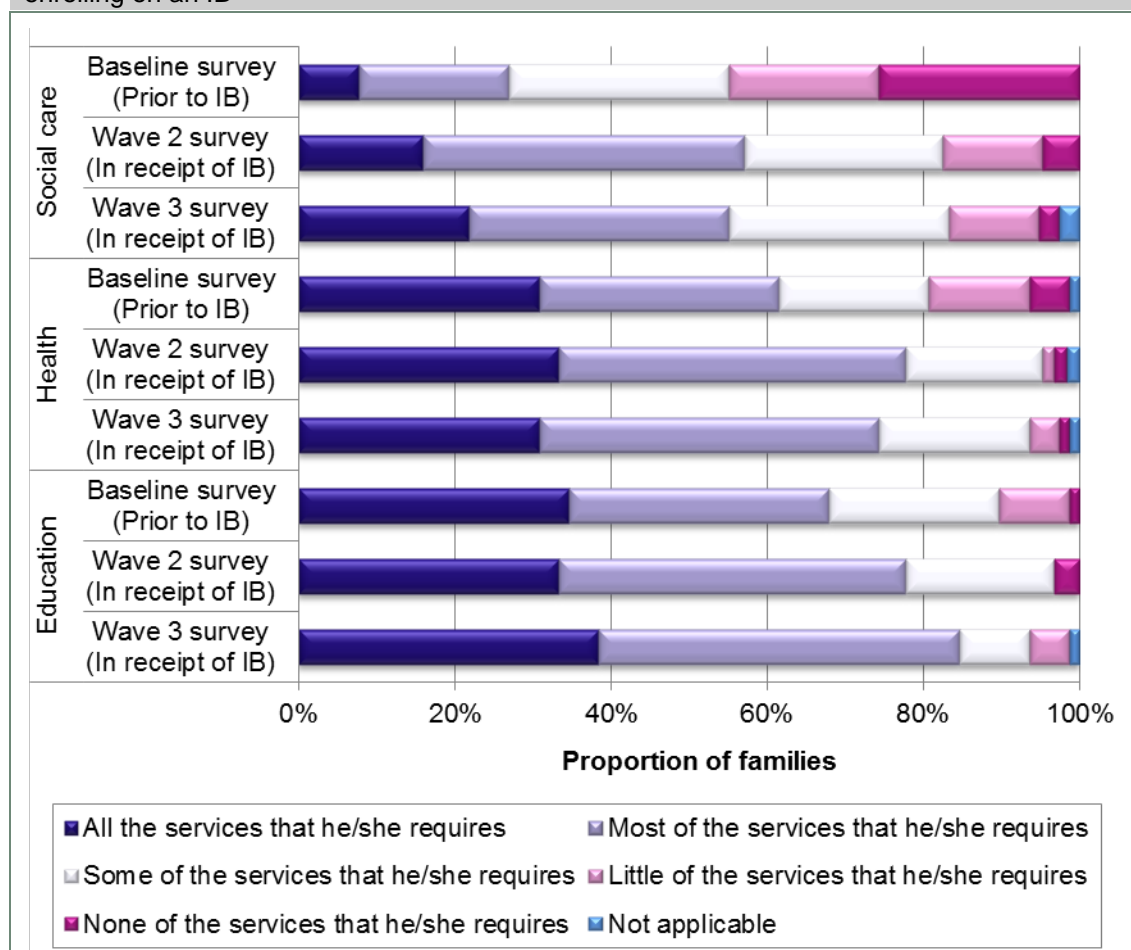
Source: SQW and Ipsos MORI Wave 1 and Wave 3 surveys

### Quality and appropriateness of care

- 4.24 By Wave 3, the majority of families had access to 'all' or 'most' of the education (85%), health (74%) and social care services (55%) that they thought their child/young person required.
- 4.25 While there had not been substantial net improvements in access to health or education provision over the course of the pilot, **access to social care increased considerably** (Figure 21). Between the baseline and Wave 2 surveys 68% of families in receipt of an IB reported that their access to social care services had improved, while 5% had access to less of the services required than at the baseline – a net improvement of +63%.
- 4.26 This widespread improvement has fallen back somewhat in the Wave 3 survey, but was still a strongly positive +47% improvement since the baseline. There were

smaller increases in access to health and education services. The changes in all three services are associated with a statistically significant overall improvement.

Figure 21: Access to services the disabled child/young person required, before and after enrolling on an IB



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

- 4.27 Forty-one percent of the families were able to access (at best) some of the social care services their child/young person required prior to IB (according to the baseline survey) and went on to gain access to 'all' or 'most' of the services they required at Wave 3 (Table 11) – a clear improvement. However some families had experienced a lessening of the services they were able to access over the course of the pilot. For instance, 11% of families went from being able to access 'most' of the services their child required at the baseline to 'some' or 'little' of them at Wave 3. As a result, at Wave 3 44% of families had access to, at best, some of the social care services they required, an improvement from 74% at the baseline.

Table 11: Access to social care services – prior to IB (Wave 1) and since enrolling on an IB (Wave 3)

		Prior to IB, had access to...	
		most/all social care services required	none/some social care services required
Since IB, has access to...	most/all social care services required	16%	41%
	none/some social care services required	11%	33%

*N=76. Figures exclude the two families who responded 'not applicable' at the baseline.*

*Source: SQW and Ipsos MORI Wave 1 and Wave 3 surveys*

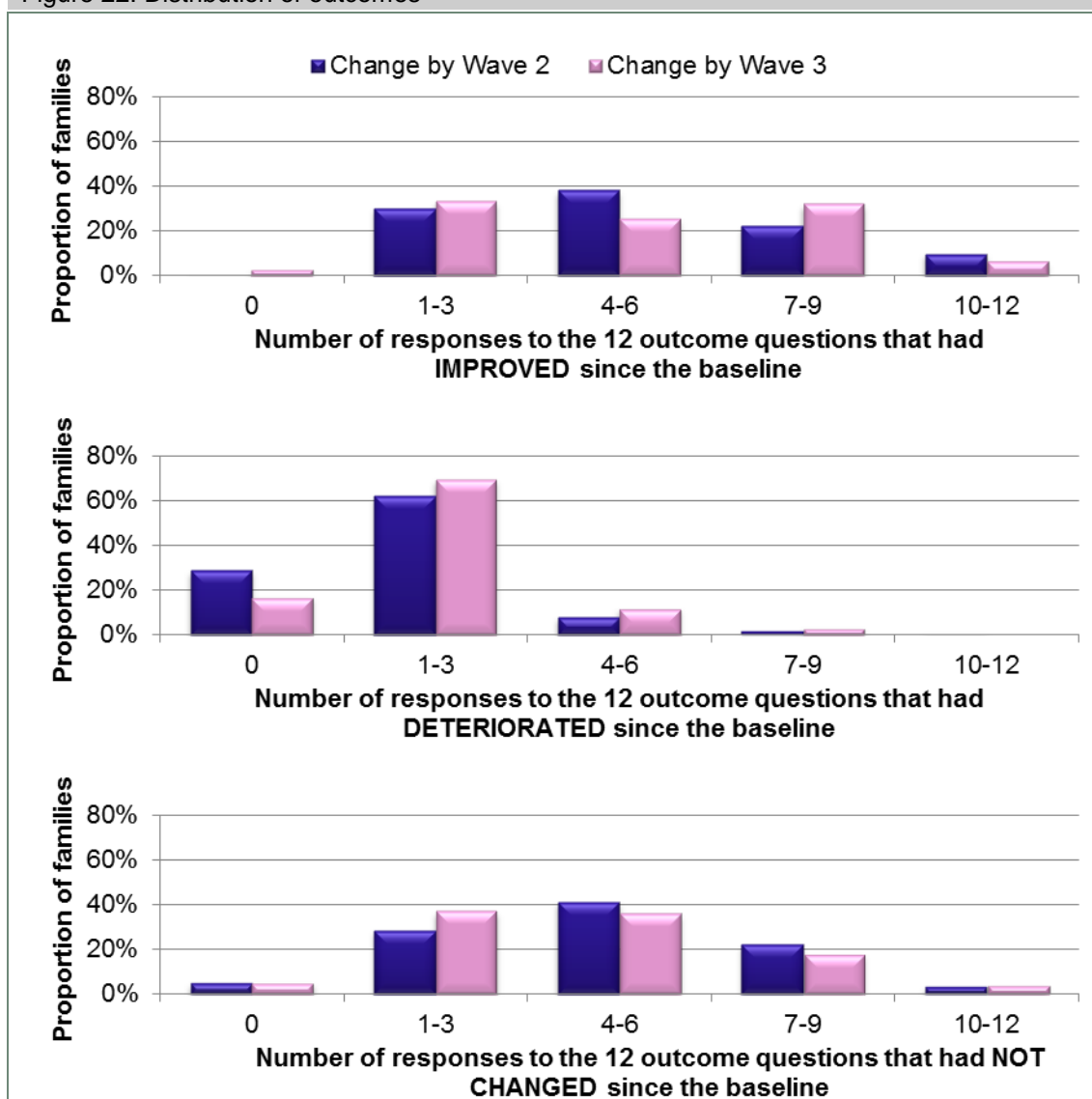
- 4.28 At the time of the Wave 3 survey two thirds of families agreed with the statement that 'the staff providing services for my child are joined up', with 26% strongly agreeing this was the case (which was associated with a statistically significant overall improvement from the baseline). Those families without previous experience of personalised approaches were more likely to agree that the staff providing services for their child/young person were joined up than those with experience of personalisation.
- 4.29 Moreover, forty-five percent of families thought that staff providing services had become more joined up since the baseline survey, although 19% had become less joined up – a net change of +26%. This change in perceptions is not substantially different from the Wave 2 survey. This probably reflects that few families from the original cohort have received extended packages.

## Distribution of outcomes

- 4.30 Overall, this chapter demonstrates a net improvement in each of the outcome measures following receipt of an IB. Improvements in outcomes were broadly sustained or built upon at Wave 3 compared to Wave 2. Across the measures the percentage of families reporting an improvement ranged from 32-68%. In this section we consider how far the individual improvements are in fact concentrated in some families or spread across the cohort.
- 4.31 The majority of families (64%) answered four or more of the 12 outcomes questions more positively in Wave 3 than the baseline, including 38% who reported improvement in more than half of the indicators. The distribution of outcomes across the cohort of families shows that benefits are spread widely and that the relationship between outcomes is complex such that some will not necessarily improve all. At the

same time most (86%) answered less than four questions more negatively suggesting that any negative effects tend not to accumulate too seriously (Figure 22).

Figure 22: Distribution of outcomes



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys<sup>17</sup>

- 4.32 Five out of the 78 families (6%) reported an overwhelmingly improved set of outcomes – answering between ten and twelve of the twelve outcome questions more positively at Wave 3 than at the baseline. There was no common feature across these families, again suggesting that benefits flow fairly widely, i.e. the high beneficiary families came from three of the pilot sites and came from a variety of backgrounds including: children with different levels of need; both newcomers to the system and existing social care users; dual and single parent households; those with and without past experience of personalisation; across both ABC1 and C2DE social

<sup>17</sup> Note: the Wave 2 figures have been recalculated since the report last year to correct a calculation error.

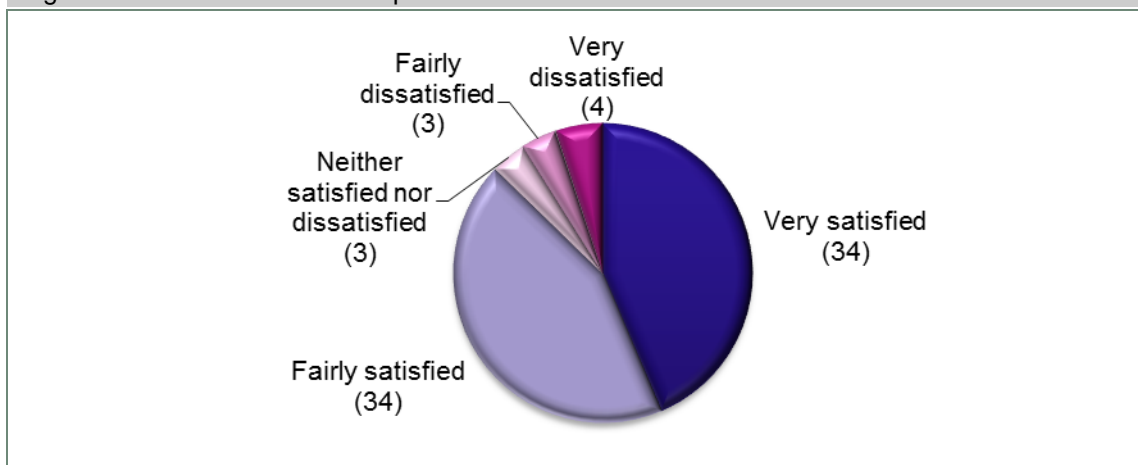


grades; and those who had had both an increase and decrease in budget from their traditional service package.

### Satisfaction with the pilot

- 4.33 The majority (87%) of families reported that they were satisfied with the IB pilot overall at the time of the Wave 3 survey (Figure 23). Existing users were more likely than newcomers to the system to be satisfied (either 'fairly' or 'very') with the system, perhaps reflecting that those in the system prior to IBs were experiencing some form of dissatisfaction.

Figure 23: Satisfaction with the pilot



N=78

Source: SQW and Ipsos MORI Wave 3 survey

## Summary

4.34 Table 12 provides a summary of findings from the chapter.

**Table 12: Summary of findings**

The survey findings indicate that 12 months after the last survey the net improvements in outcomes have generally been sustained at Wave 3, but in most cases have not become more widespread.

Despite already having relatively high levels of involvement in decision making prior to receiving an IB, the IB has increased perceived levels of control over provision for some families. The following net improvements<sup>18</sup> had been witnessed by Wave 3:

- +27% improvement in the involvement of parents in decisions affecting the care of their disabled child/young person (compared to +22% by Wave 2)
- The majority of families experienced an increase in control over the help they receive in relation to their child/young person's disability (net improvement of +54% by Wave 3).

Satisfaction with the help received in relation to their child/young person's disability also improved (a net improvement of +45% by Wave 3).

On average, families spent the same amount of time accessing, coordinating and overseeing services through their IB as their traditional service provision.

Access to the social care services required has increased considerably since the baseline (a net improvement of +47% by Wave 3). While still strongly positive, this net improvement has fallen back from the +63% improvement reported in Wave 2.

The improved outcomes were fairly widely distributed across families. While some reported more improvement than others, most reported at least some improvement.

<sup>18</sup> Net improvement relates to the proportion of families reporting an improved position from the baseline minus the proportion of families reporting being in a worse position.

## 5: Impacts achieved by the original cohort of participating families

### Introduction

- 5.1 This chapter focuses on the impacts that have occurred following the outcomes reported in the previous chapter. It therefore considers how far improved choice and control, or access to services can improve family wellbeing, or occur as endpoints in themselves.
- 5.2 Table 13 sets out the logic chain developed as part of the evaluation framework, showing both the anticipated link from outcomes the impacts, and the types of impacts which the study has sought to measure. The impacts are considered against the elements of the Every Child Matters framework which was selected in 2009 as the basis against which the original set of pilot impacts were developed:
- Be healthy
  - Stay safe
  - Enjoy and achieve
  - Making a positive contribution
  - Achieve economic wellbeing.

Table 13: Beneficiary related outcomes and impacts framework

OUTCOMES	Disabled Child/Young Person outcomes/impacts	Theme	Family-based outcomes/impacts
	Increased user satisfaction with service provision	← <b>INCREASED CHOICE AND CONTROL</b> →	Increased user satisfaction with service provision
	Increased control over daily life		Increased control over daily life
	Increased personal costs e.g. increased responsibility		Increased responsibility of coordination/personal costs
	Improved access to more appropriate services	← <b>QUALITY AND APPROPRIATENESS OF CARE</b> →	Improved access to more appropriate services
Greater continuity of care	Greater continuity of care		
Improved quality of care	Improved quality of care		
Fewer unmet needs	Fewer unmet needs		
↓			

Disabled Child/Young Person outcomes/impacts			Theme		Family-based outcomes/impacts	
IMPACTS	Improved health (self perceived) Increased user satisfaction with service provision	←	BE HEALTHY	→	Improved health (self perceived) Reduction in family stress levels Increased user satisfaction with service provision	
	Increased sense of safety when undertaking activities both inside and outside of the home	←	STAY SAFE	→	Reduced anxiety associated with child undertaking activities inside and outside of the home	
	Increased enjoyment of learning/school Improved educational attainment	←	ENJOY AND ACHIEVE	→	Increased labour market participation Improved educational attainment of siblings	
	Increased self confidence Increased independence Increased social engagement and participation in the community	←	MAKING A POSITIVE CONTRIBUTION	→	Increased parental confidence	
	Increased range of social and economic opportunities available Improved quality of life Increased labour market participation or engagement in non-compulsory education (for children in transition)	←	ACHIEVE ECONOMIC WELL BEING	→	Wider range of social and economic opportunities available Improved quality of life Strengthened family units Increased labour market participation or engagement in non-compulsory education (for children in transition)	

*Note: Content that relates to impacts is greyed out and is discussed in the next chapter.*

*Source: SQW Individual Budgets Evaluation Briefing Note*

- 5.3 The data reported in the Wave 2 survey was gathered shortly after many IBs went live. At Wave 2 it remained to be seen whether the benefits reported would be sustained over time, or whether they would change as people acclimatised to the new package of support and experienced the effects of their IB on different aspects of their lives. The extension of the evaluation and subsequent Wave 3 survey enabled us to consider impacts again, one year on from the Wave 2 survey, to examine the extent to which impacts have been sustained or experienced more widely over time.

## Impacts

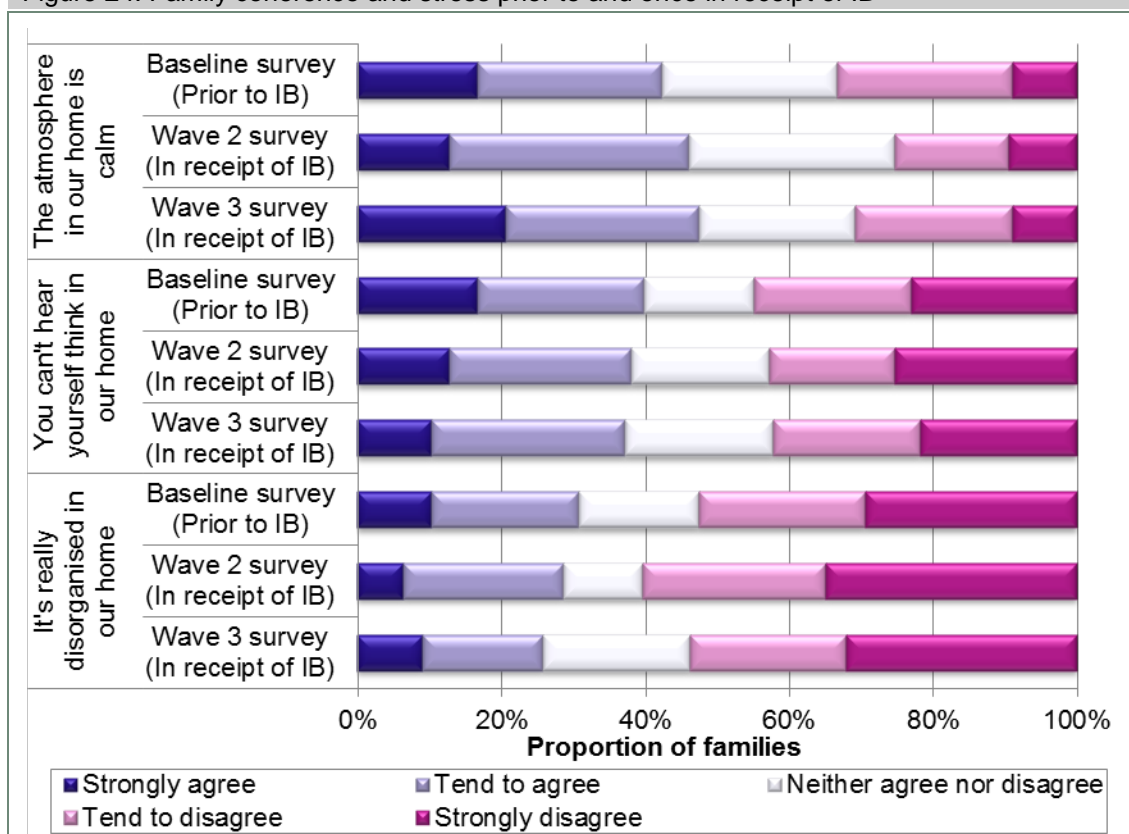
### ***Be healthy***

- 5.4 There were not widespread statistically significant aggregate changes in the indicators of family coherence between the baseline and Wave 3 surveys (Figure 24), meaning we were unable to rule out the possibility that the changes occurred by chance rather than reflecting a pattern of improvement which would be replicated

across a wider population. However there have been some underlying changes at the individual level:

- The atmosphere in 35% of homes was perceived to be more calm at Wave 3 compared to baseline, while 23% of homes became less calm – a net improvement of +12%
- 31% of families felt it was less disorganised in their home, while 28% felt it was more so – a net improvement of +3%.

Figure 24: Family coherence and stress prior to and once in receipt of IB



N=78<sup>19</sup>

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 surveys

- 5.5 Around a quarter (24%) of parents reported that their child's health had improved since the baseline survey, while 21% of children/young people's health was reported to have deteriorated by Wave 3. A few of the IB families from the original cohort received health funding through their IB, which may have contributed to their child/young person's health needs being met. Changes in activity such as the increased use of leisure facilities could also have contributed to more healthy lifestyles. It is therefore possible that the IB process made some contribution to the

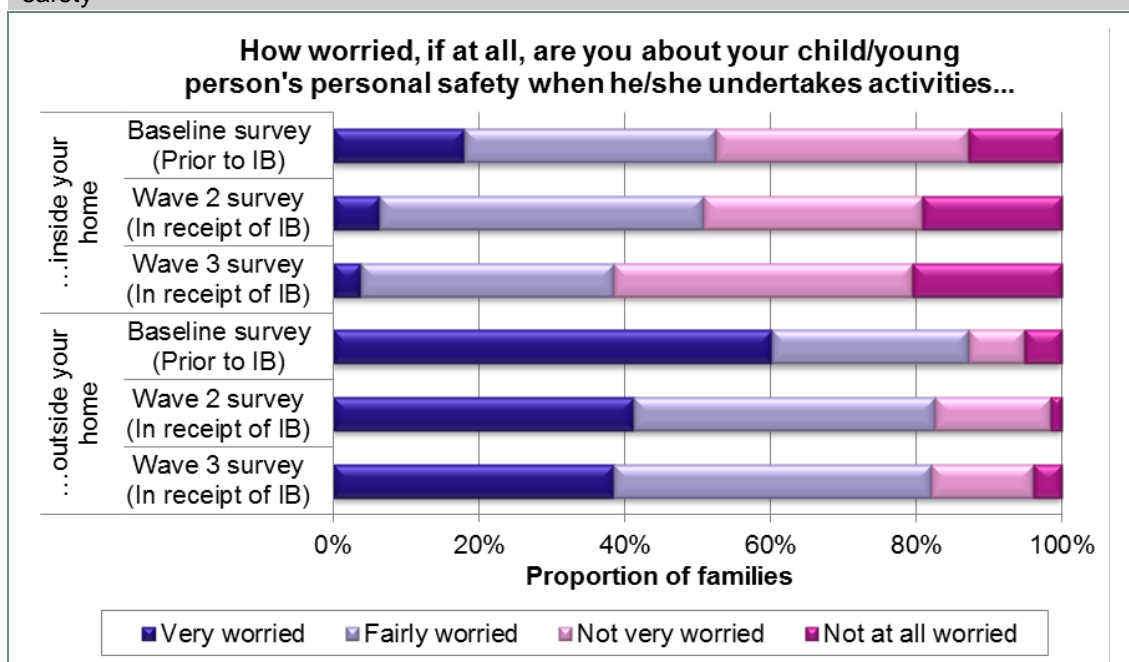
<sup>19</sup> In waves 2 and 3, responses are only included from families who were in receipt of their IB at the time of the survey. This includes 63 families in Wave 2 and 78 families in Wave 3.

reported changes, although factors outside of the pilot are likely to have been significant such as changes in wider health provision.

### **Stay safe**

- 5.6 The pilot has provided children/young people with increased opportunities to socialise through the use of personal assistants, and so led to changes in perceptions of what children were able to do while remaining safe. By Wave 2, a large minority of parents in receipt of an IB were less anxious about their children undertaking activities inside (37%) and outside (38%) the home than at the baseline (Figure 25). Conversely, a number of parents reported at Wave 2 becoming more worried about their child's safety when undertaking activities inside (22%) and outside (11%) the home. On balance there were net improvements of +14% and +27% respectively. These net improvements have been largely sustained at Wave 3, both in terms of decreased concern when the children/young people undertake activities inside (+19%) and outside (+24%) the home, with both changes being associated with a statistically significant overall improvement.
- 5.7 However, the majority of families continued to be fairly or very worried about their child/young person's safety when undertaking activities outside the home. The changes in concern between the baseline and Wave 3 tended to be in relatively small increments. For instance parents tended to move from being 'very worried' to 'fairly worried' (in 22% of families) or from 'fairly worried' to 'not very worried' (in 9% of families) rather than from 'very worried' to 'not at all worried'. This may reflect general parental anxieties about their children, alongside a reflection of the level of needs of this group of young people.

Figure 25: Extent to which parents are concerned about their child/young person's personal safety



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

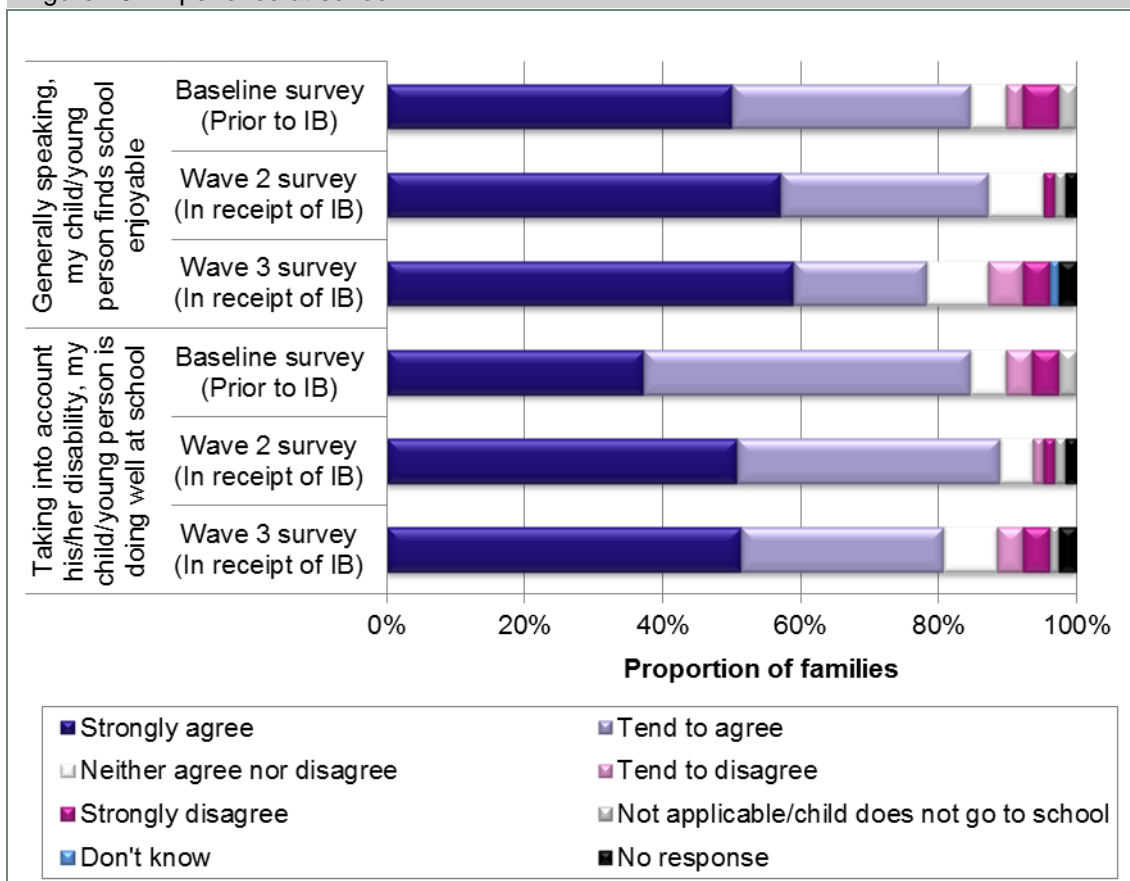
- 5.8 Many families used their IB to employ a personal assistant (PA). *The Family Journey* report<sup>20</sup> discusses family experiences of PAs in more detail, including examples of PAs accompanying child/young people in activities outside the home. Increased use of and confidence in PAs may have led to these perceived improvements in child safety.

### **Enjoy and achieve**

- 5.9 Figure 26 shows parent perceptions of their children's experience at school across the three waves of the survey. One quarter of parents rated their child's attainment at school more highly at Wave 2 than in the baseline survey, while 11% rated their child's school performance as lower - a net improvement of +14%. By Wave 3 the proportion of parents reporting an increase in their child's school attainment (compared to the baseline) had increased to 33%, although the number of parents whose child's attainment was lower than baseline had also increased to 18% - resulting in a similar level of net change (+15%). The overall improvements in enjoyment and attainment at school were *not* statistically significant.

<sup>20</sup> Johnson, R., Thom, G., Prabhakar, M., 2010, *Individual budgets for families with disabled children: Final evaluation report: The family journey*

Figure 26: Experience at school



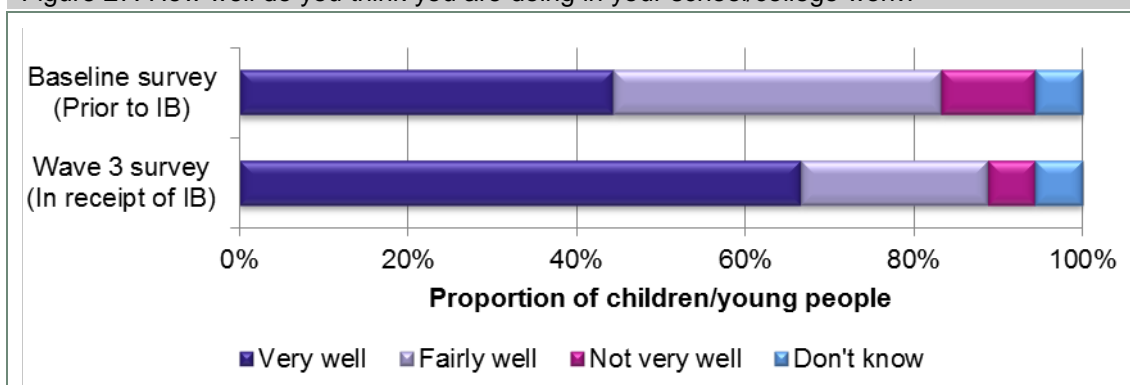
N=78

No response includes families where the young person was over the age of 16 but not in school, college and training. It also includes families who were not in receipt of their IB at the time of the Wave 2 survey.

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

- 5.10 At Wave 3, twelve of the 18 children/young people consulted felt they were doing 'very well' at school, compared to eight at the baseline (Figure 27).

Figure 27: How well do you think you are doing in your school/college work?



N=18

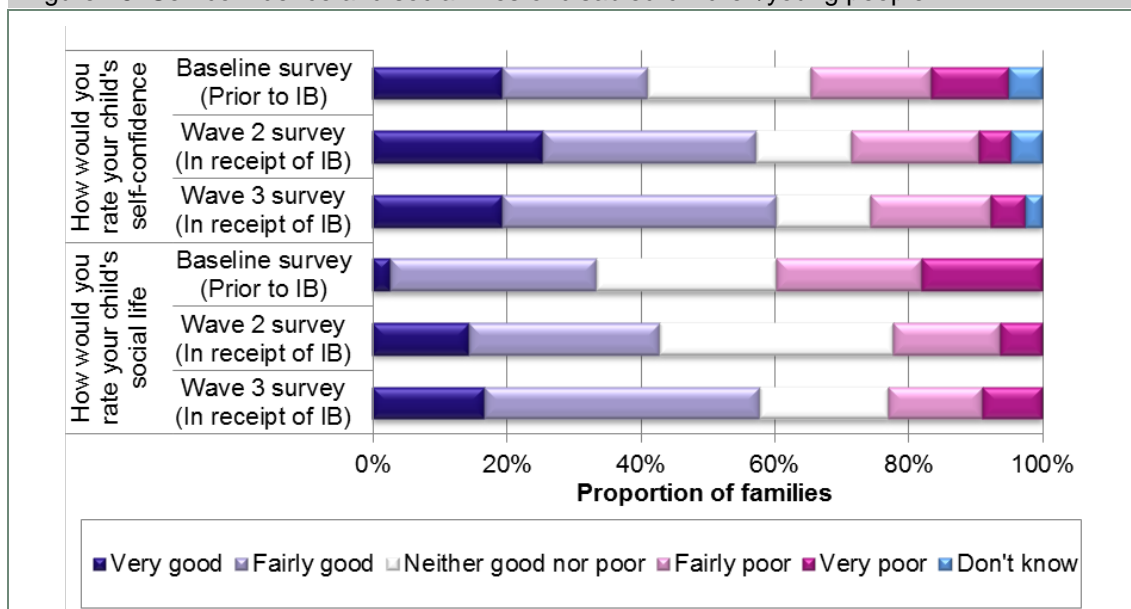
Source: SQW and Ipsos MORI Wave 3 survey



### ***Making a positive contribution***

- 5.11 Improvements in the children's social lives (again often related to the increased use of PAs) were among the biggest changes in impact indicators noted at Wave 2 and remained so at Wave 3 (Figure 28). Around half (49%) of responding parents reported improvements in their child's social life compared to the baseline, while 14% rated their child's social life worse in Wave 3 – a net improvement of +35%. Fifty eight percent of families rated their child's social lives as either 'fairly' or 'very good' by Wave 3, including almost half (45%) of the families who had rated their child/young person's social life as poor at the baseline.
- 5.12 Correspondingly, the net improvement in children's self confidence was +18% between the baseline and Wave 3 surveys (similar to the +16% at Wave 2), which was associated with a statistically significant overall improvement.

Figure 28: Self-confidence and social lives of disabled children/young people

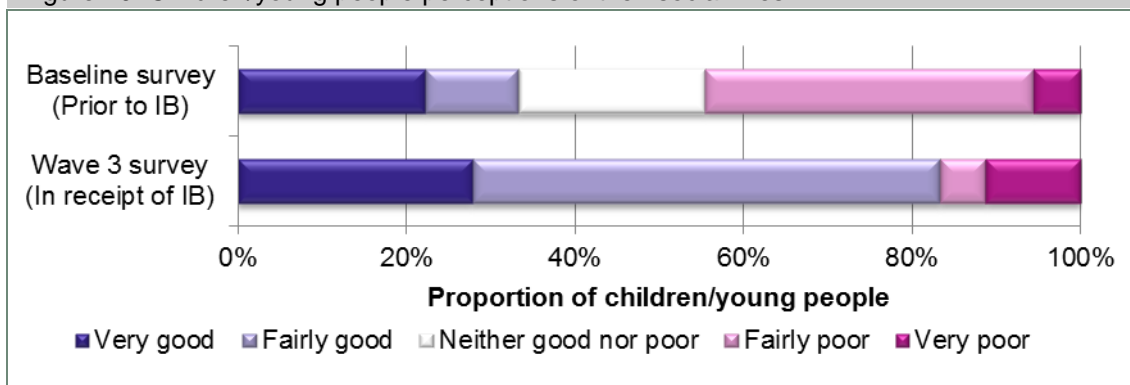


N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

- 5.13 As Figure 29 illustrates, the majority of the 18 children/young people surveyed also perceived their social lives to have improved since enrolling on the pilot.

Figure 29: Children/young people perceptions of their social lives

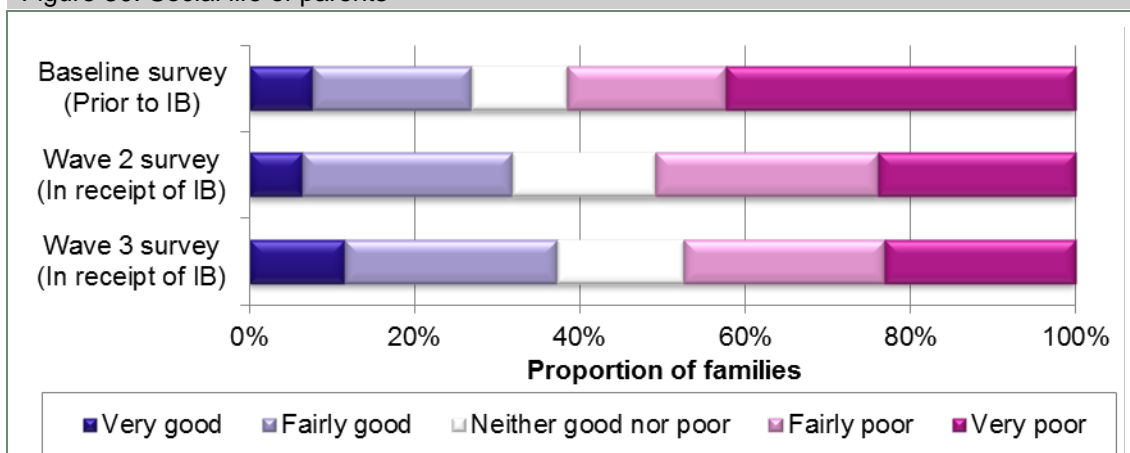


N=18

Source: SQW and Ipsos MORI Wave 1 and Wave 3 survey

- 5.14 Parent social lives have improved substantially over the life of the pilot (Figure 30). By Wave 3, 44% of parents rated their social lives higher than at baseline, while 17% of parents rated their lives lower – a net improvement of +27%, which was associated with a statistically significant overall improvement. This is a six percentage point increase on Wave 2, where there was a net improvement of +21%.

Figure 30: Social life of parents



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

### ***Achieve economic wellbeing***

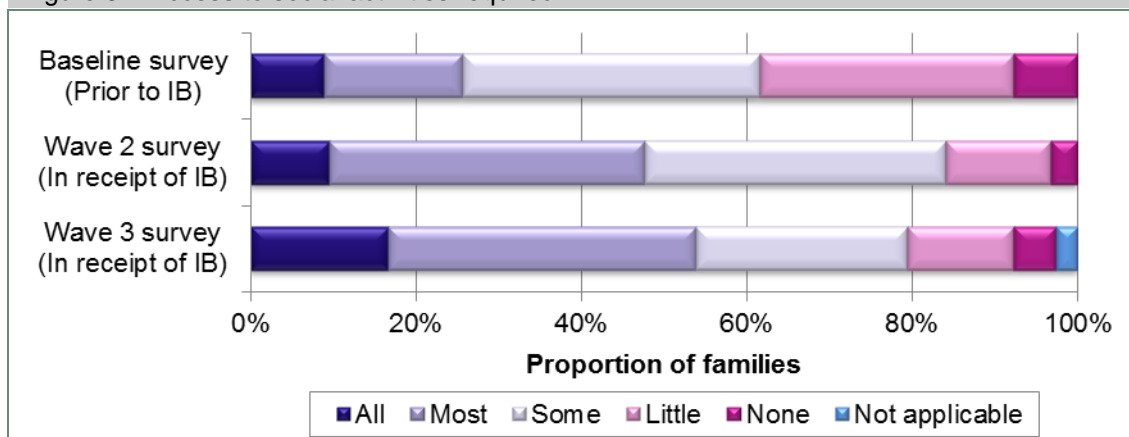
- 5.15 Six parents who were not in work at the time of the baseline survey had entered employment by Wave 3 (two into full-time and four into part-time work). While relatively small in number this is a significant change for these families. *The Family Journey*<sup>21</sup> discussed individual family stories of where the pilot had enabled parents to enter employment. However five of the surveyed parents reported being out of work at Wave 3 after being in work at the baseline.

<sup>21</sup> Johnson, R., Thom, G., Prabhakar, M., 2010, *Individual budgets for families with disabled children: Final evaluation report: The family journey*

5.16 Figure 31 illustrates the sizeable improvements in the social activities the children/young people were able to access after enrolling on an IB. The number of parents who perceived their child had access to all or most of the social activities he/she required more than doubled from 26% to 54% between the baseline and Wave 3 surveys. Around half (51%) of parents reported that their child had access to more social activities at Wave 3 than at the baseline, although 21% reported that their child had access to less – a net improvement of +31%, which was associated with a statistically significant overall improvement .

5.17 Those families reporting having a great deal of control over the help they receive in relation to their child/young person's disability at Wave 3 were more likely to report that the child had access to most or all of the social activities they required. Indeed, 85% of the families who reported having access to all or most of the social activities they required at Wave 3 also reported having a great deal of control over the help they receive, while the remaining 15% all had a fair amount of control over their help.

Figure 31: Access to social activities required



N=78

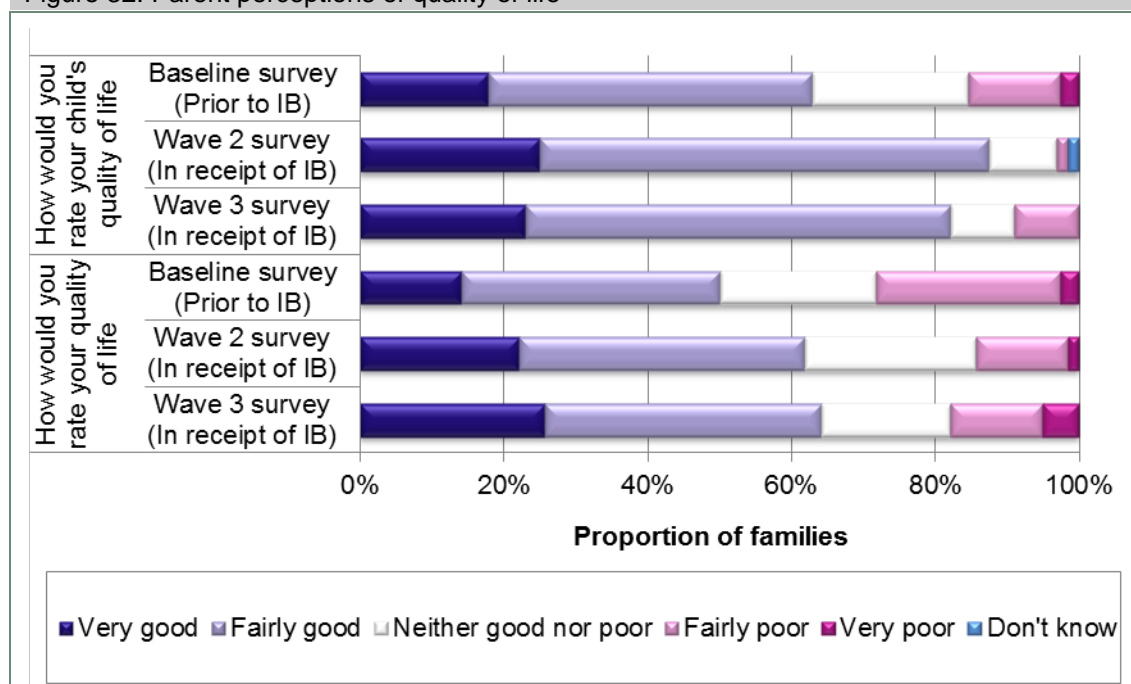
Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

5.18 As an overall indicator of wellbeing, improvement in child's quality of life is encouraging (Figure 32). Forty-one percent of families in receipt of an IB rated their child's quality of life as higher than at the baseline. Just 8% rated their child's quality of life as worse – a net improvement of +33%. While the net improvement has fallen somewhat in the past year as a result of the larger proportion (14%) of families who rated their child's quality of life as lower than at the baseline, the improvement remains clear and was associated with a statistically significant overall improvement.

5.19 At Wave 3, 82% of families rated their child/young person's quality of life as very or fairly good; including two thirds of the 12 families who had reported their child's quality of life to be very or fairly poor at the baseline.

- 5.20 Two fifths of parents have also experienced improvements in their own quality of lives during the pilot (Figure 32). Thirty-nine percent of parents reported that their quality of life was better at Wave 3 than at the baseline, while the quality of life of 15% of parents was perceived to have deteriorated. As such, there was a net improvement of +23%; which was associated with a statistically significant overall improvement and in line with the improvement seen at Wave 2.

Figure 32: Parent perceptions of quality of life



N=78

Response listed as 'N/A' where family was not in receipt of their IB at the time of the Wave 2 survey

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

- 5.21 Families with higher levels of control over the help they received for their child/young person's disability at Wave 3 were more likely to report that they had a fairly or very good quality of life. Ninety-two percent of families who had a great deal of control over their lives perceived their child/young person to have a fairly or very good quality of life, compared to 82% of all the families surveyed. Similarly, those parents reporting increased control over their family lives also reported improved quality of life. Over half (58%) of families whose control over their daily life had improved over the course of the pilot also reported improved quality of life (while 11% reported a deterioration in their quality of life – a net improvement of +47%, which was associated with a statistically significant overall improvement).
- 5.22 Almost half of the parents (46%) reported that they found it less difficult to provide others in the household with the support they needed at Wave 3 than when they completed the baseline survey. Although 14% found it harder to provide support, the

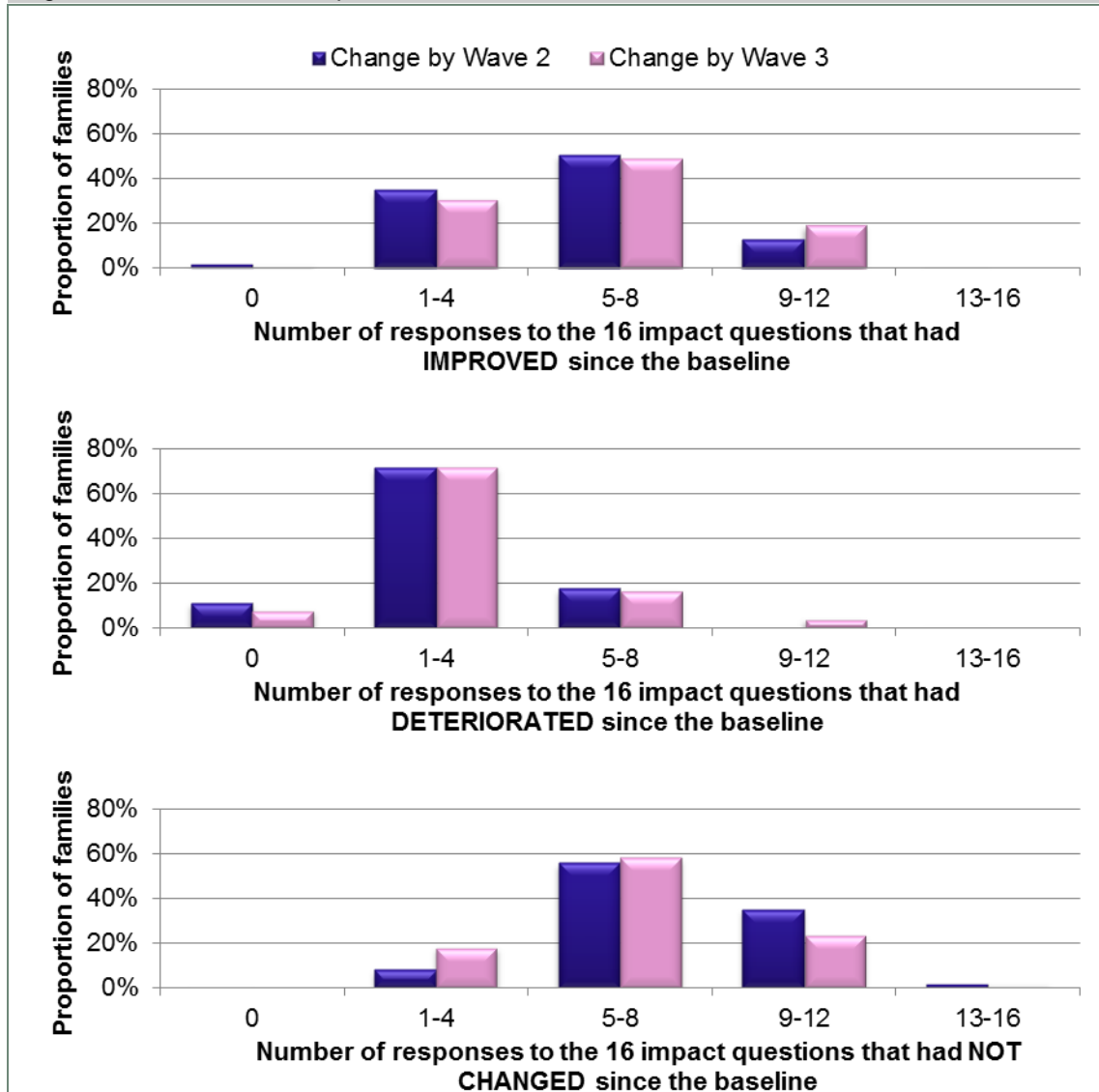
net improvement was +32%, which was associated with a statistically significant overall improvement. This was a marked improvement from Wave 2 (where there was a net improvement of +21%) both as a result of an increased proportion of parents reporting improvement from the baseline and a decreased proportion reporting deterioration from the baseline.

- 5.23 However, in cases where the intensity of disability of the child/young person became more severe throughout the pilot, families were more likely to report increased difficulty providing others in their household with the support they needed.

### Distribution of impacts

- 5.24 At Wave 3 68% of the families reported improvements across at least 5 of the impact indicators, compared to 63% at Wave 2 (Figure 33). This suggests that the improvements in impact indicators reported at Wave 2 have been sustained at Wave 3 and built upon in some cases. The extent to which impacts have been recorded appears slightly lower than the outcomes reported above. That said, the overall pattern is similar to that for outcomes, suggesting a fairly widespread set of benefits.
- 5.25 However, more families reported deterioration in five or more impact indicators at Wave 3 than Wave 2 (21%, up from 17%). Combined with an overall fall in the number of “no change” responses, this implies that variation increases with time from baseline, most likely due to a combination of factors within and outside the pilot.

Figure 33: Distribution of impacts



N=78

Source: SQW and Ipsos MORI Wave 1, Wave 2 and Wave 3 survey

## Summary

5.26 Table 14 provides a summary of findings from the chapter.

Table 14: Summary of findings

### Summary findings and lessons

One year on from Wave 2 the net improvements in impacts have, for the most part been sustained, although they have not been experienced more widely as families acclimatised to their new packages of support.

Changes over the course of the pilot (baseline to Wave 3) are set out below against elements of the Every Child Matters framework:

- **Be healthy** – While there have not been significant aggregate changes in perceptions of family coherence by Wave 3, 35% of homes were perceived to be more calm by Wave 3 while 23% were less calm – a net improvement of +12%.
- The health of a quarter (24%) of children/young people was perceived to have improved since the baseline, while the health of 21% had deteriorated (the overall improvement was not statistically significant). Given the limited direct engagement of health, factors outside the pilot are also likely to have been key.
- **Stay safe** – Since enrolling on the pilot, there have been net decreases in levels of parental concern over the children/young people's safety when undertaking activities inside (+19%) and outside (+24%) the home. The pilot has provided children/young people with increased opportunities to socialise through the use of personal assistants.
- **Enjoy and achieve** – There has been some net improvement in perceptions of the children/young people's attainment (+15%) and enjoyment (+9%) of school since the baseline (although the overall improvement was not statistically significant).
- **Making a positive contribution** – Since the baseline, there have been net improvements in both parents (+27%) and their children's (+35%) social lives. Increased use of personal assistants is likely to have been a factor in these improvements.
- **Achieve economic wellbeing** – 39% of the children/young people had experienced an improvement in their quality of life by Wave 3, along with 39% of parents. Conversely 14% and 15% of parents reported deterioration in their children's and their own quality of life respectively (net improvements of +25% and +24%). Six parents also entered employment from the baseline, in some cases as a direct result of the pilot.

## 6: Conclusions and implications

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- 6.1 This final chapter draws together the evidence presented above to reach a series of conclusions about the longer term effects of the IB approach. The conclusions give rise to a discussion about the implications of the findings.

### The IB process

- 6.2 Most families in the pilot that engaged in the IB process have remained in receipt of their IB package. Very few families have dropped out following the IB going live. Those that have dropped out tended to do so before the IB went live due to issues around the size of the budget and/or because they are broadly content with their exiting package.
- 6.3 The feedback from staff and families about the process of review reinforces this positive message. Families were generally content that the review had taken their views into account and not been unduly onerous. Moreover, they had used the review to slightly alter their packages to better suit their needs (both because needs had changed, or they had new ideas about what would be appropriate).
- 6.4 Together the high level of retention and the good feedback about the reviews would strongly suggest that **many families in the pilot have accepted and welcomed the IB approach.**

### The outcomes achieved

- 6.5 The reasons behind families' satisfaction with the process are indicated by the results presented in Table 15 (which summarises the results presented in Chapter 4). There were statistically significant improvements in almost all of the outcome indicators.

**The most frequent improvements reported after receipt of an IB are:**

- **Access to social care services**
- **Control over services received**
- **Satisfaction with the support received.**

- 6.6 It is likely that these bullet points reinforce each other, i.e. that improved access and control will lead to increased satisfaction. That said, it is interesting that satisfaction has actually gone up least of the three indicators, perhaps suggesting how



challenging some circumstances or indeed family demands are (or perhaps that levels of expectation have risen over the life of the pilot).

- 6.7 There were also fairly large and statistically significant improvements on most of the other outcome indicators, with all above +20% net improvement. These improvements appear to have been sustained over the 12 months since the previous study, **suggesting a good degree of sustainability of outcomes**. As such, families get an initial boost in terms of service access and control through an IB, and this remains in place as the new approach becomes the norm.

Table 15: Change in outcomes for families

Issues	Wave 2 Survey			Wave 3 Survey		
	% reporting improved position from baseline	% reporting worse position than at baseline	Net change	% reporting improved position from baseline	% reporting worse position than at baseline	Net change
Parents are involved in decisions	32	10	+22	37	10	+27
Parents are kept informed about decisions	41	11	+30	41	17	+24
Control over services	64	6	+57	65	12	+54
Satisfaction with support received	56	13	+43	59	14	+45
Control over daily lives	43	6	+37	46	12	+35
Access to social care services	68	5	+63	62	14	+47
Staff appear joined up	49	21	+29	45	19	+26

*Net change figures may not equal improvement – worsening due to rounding.*

*Wave 3 figures include responses from the 78 families who answered the Wave 1, Wave 2 and Wave 3 surveys and were in receipt of their IB by the Wave 3 survey. Wave 2 figures include responses from the 63 families who answered the Wave 1, Wave 2 and Wave 3 surveys and were in receipt of their IB by Wave 2.*

*Source: SQW and Ipsos MORI Wave 1, 2 and 3 surveys*

- 6.8 **The benefits were fairly widespread**, with almost two-thirds of families reporting improvements in four or more of the outcome indicators. This suggests that most of those participating gained something. Moreover, any negative effects were similarly widespread. This suggests that on the whole most families will gain some level of satisfaction from the IB approach.
- 6.9 The widespread nature of the benefits is more encouraging given that for a number of families the amount of time that they spent managing services increased after

receipt of an IB. Conversely, for more complex cases / those requiring more management previously, there was a tendency for the amount of time required to decrease.

- 6.10 Although most families gained something, it also appears that **those most likely to report improved outcomes are those who were initially less satisfied**. So, while some families who were satisfied to begin with became more satisfied; it was more common for families who were not previously satisfied to become satisfied across a number of the indicators.
- 6.11 This is potentially **important in terms of any wider roll out as the extent of any gains in outcomes achieved will depend on the initial level of satisfaction**. So where families are satisfied to start with, they are less likely to report positively on any changes. Already satisfied families are unlikely to be unhappy with any changes, but it would suggest that the value for money of such changes may be lower. **It would also indicate that in targeting or phasing any rollout it may be best to begin with those families that are expressing dissatisfaction as this is where most benefit will be gained**. Indeed, this type of 'problem solving' approach is one that we have observed in the IB pilots whereby the IB approach has been used to provide a more tailored and flexible approach to difficult cases.

### The impacts achieved

- 6.12 It was anticipated in the evaluation framework that improved outcomes would lead to changes in longer term impacts, i.e. that improved choice and control and service receipt would improve the social and economic wellbeing of the child/young person and the family. However, although there **were positive net changes across the impact variables, only around two thirds of these were associated with a statistically significant overall improvement** (Table 16).
- 6.13 **The most commonly reported impacts are the improved social life of both the child/young person and the family, and improved family togetherness**. These impacts are similar to those reported in the previous wave of the survey, again indicating that **where benefits arise they tend to be maintained**.

Table 16: Change in impacts for families – changes associated with a statistically significant improvement are in bold

Wave 2 Survey				Wave 3 Survey		
Issues	% reporting improved position from baseline	% reporting worse position than at baseline	Net change	% reporting improved position from baseline	% reporting worse position than at baseline	Net change
<b>Be healthy</b>						
Home is calm	35	22	+13	35	23	+12
Home is disorganised	32	21	+11	31	28	+3
<b>Be safe</b>						
Concern over child's safety – in home	<b>37</b>	<b>22</b>	<b>+14</b>	<b>42</b>	<b>23</b>	<b>+19</b>
Concern over child's safety – outside home	<b>38</b>	<b>11</b>	<b>+27</b>	<b>37</b>	<b>13</b>	<b>+24</b>
<b>Enjoy and achieve</b>						
Attainment at school	25	11	+14	33	18	+15
Enjoyment of school	21	14	+6	24	15	+9
<b>Making a positive contribution</b>						
Child's social life	<b>59</b>	<b>21</b>	<b>+38</b>	<b>49</b>	<b>14</b>	<b>+35</b>
Child's self confidence	<b>30</b>	<b>14</b>	<b>+16</b>	<b>35</b>	<b>17</b>	<b>+18</b>
Parents social life	<b>38</b>	<b>18</b>	<b>+21</b>	<b>44</b>	<b>17</b>	<b>+27</b>
<b>Achieve economic wellbeing</b>						
Child's quality of life	<b>41</b>	<b>8</b>	<b>+33</b>	<b>39</b>	<b>14</b>	<b>+24</b>
Parents quality of life	<b>38</b>	<b>16</b>	<b>+22</b>	<b>39</b>	<b>15</b>	<b>+23</b>
Family strength	<b>41</b>	<b>21</b>	<b>+21</b>	<b>46</b>	<b>14</b>	<b>+32</b>

Net change figures may not equal improvement – worsening due to rounding.

Figures include responses from the 78 families who answered the Wave 1, Wave 2 and Wave 3 surveys and were in receipt of their IB by the Wave 3 survey. Wave 2 figures include responses from the 63 families who answered the Wave 1, Wave 2 and Wave 3 surveys and were in receipt of their IB by Wave 2.

Source: SQW and Ipsos MORI Wave 1 and Wave 3 surveys

6.14 The **reported impacts are considerably less widespread than the achieved outcomes**, and some were not statistically significant. The net change in impacts ranges from 3-35%, compared to 24-54% for outcomes. We had anticipated that the level of impacts would grow over time as a result of families improved access to services that better suited their needs. This chain of impact appears not to have developed as hoped, and given the time that has passed it seems unlikely that they will. This is concerning because it is improvements in impact that would lead to long term returns on the investment made to introduce the IB. Moreover, the nature of the improvements around social life are hard to value in economic terms.

6.15 The apparently limited impacts could be because:

- The issues faced by these children/young people and their families are so significant that changes in service can have only a marginal effect, even where families become happier with the support delivered
- Some of the impact indicators refer to issues that are likely to be affected by wider service delivery, and where the IB as it developed had less traction than envisaged originally (such as around education and health). The delivery of the SEND Pathfinder programme, with its focus on a more holistic approach should test this issue further.

## Concluding thoughts

6.16 While the level of impacts has not increased as hoped, it should be remembered that **most families did report improvements on some indicators and that most families are happier with the support that they receive**. And, as with outcomes, there are relatively limited negative effects in terms of impacts. So, **if going forward the key policy objective is simply to increase choice and control, then that has broadly been achieved. If however, the expectation is that choice and control will in turn improve impacts, then the results are less conclusive**.

6.17 The rollout of IBs is likely to have the biggest effect where: there are a significant group of dissatisfied families, whose issues could be addressed through the IB approach; and perhaps where a more holistic approach is taken to increase the likelihood of improvements across social care, health and education and at the same time share the costs of development across the partners.

6.18 In effect **this leaves a dilemma around both the IB approach** as piloted and the wider SEND Pathfinders. One option would be to **limit investment in the new**

**approach to focus on families that are unhappy with their current offer.** Perhaps where families are broadly happy with their current support then in moving to an IB approach the level of investment around these families should be fairly limited. For example, the amount of time and effort invested in support planning could be limited on the grounds that relatively little needs to change.

- 6.19 This of course assumes that it can be known which families are satisfied or not with their services. In some cases, especially for vocal families this will be possible. For others, some form of segmentation may be required, perhaps through some initial questioning about how much the family would hope to change.

The second, more positive, option to the dilemma is to **take the initially more expensive, holistic approach in the expectation that this will lead to greater benefits.** The evidence generated by the on-going SEND Pathfinders will be crucial in demonstrating if these greater benefits can be evidenced.

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